Professionals Talk about Parents with Learning Disabilities

Deborah Chinn

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Declaration and Word Count

I hereby declare that, except where explicit attribution is made, the work presented in this thesis is entirely my own.

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Deborah Chinn

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Abstract

Although parents with learning disabilities have attracted academic and professional attention because of concerns about their ability to care adequately for their children, there has been little systematic development of services for these families. This study seeks to understand the barriers to progress by investigating the issues faced by professionals who work with these parents.

I investigate how professionals understand these parents, and clarify how these perceptions link to broader socially defined categories of competence, childhood, parenting and professional practice. I show how social constructions of disabled recipients of professional interventions, and of children, shape and constrain practice, with emphasis on the dilemmas and contradictions that practitioners face.

I use a discourse analysis approach informed by discursive psychology and Foucault to examine transcribed interviews with twenty health and social care professionals who have had experience of working with learning disabled parents and their children. Dominant discourses emphasise, on the one hand the incompetence of learning disabled people as social actors and as parents, and on the other children's vulnerability and dependence. I investigate how practitioners attempt to reconcile what they perceive as their responsibility to promote 'normal' family life backed up by expert knowledge with an expectation that they acknowledge conceptions of human rights and client 'empowerment'. I challenge polarised views of professionals as either altruistic public servants or all-powerful oppressors of disabled people. I argue that their options for action are limited by a professional climate preoccupied with risk and accountability. Nevertheless I identify examples of resistance to these dominant discourses, suggesting that further progress will be made when practitioners are encouraged to adopt a more critical approach to often taken-for-granted assumptions about disability, parenting and children.

Contents

Chapter One: Introduction to the Study

1.1 Preliminary remarks

This research looks at how professionals who work with parents with learning disabilities talk about their work. Much research has focused on the inadequacies of this group of parents (as I review in detail in my literature review), and it does seem more likely that these parents will come into contact with child welfare services and have their children removed compared to other groups of parents. Professionals who work with these parents are exposed to assumptions about the inadequacies of these parents, but increasingly are expected also to consider ideas about human rights and the empowerment of clients. I am interested in how the professionals negotiate a balance between these complex and sometimes conflicting ideas.

Increasing research interest and professional scrutiny does not appear to have been translated into widespread or systematic changes in provision for these parents, though isolated initiatives to support them continue to spring up around the country (Young et al., 1997; McGaw et al., 2002; Booth and Booth, 2003a). By talking to professionals themselves my intention is to address the fundamental question of why services, despite good intentions and commitment to good practice, appear to continue to act in the way that they do, often with painful, life-changing consequences for parents and their children (Booth and Booth, 1994).

In this chapter I explain why I have focused on professionals' views (further discussion of the implications of not including parents as participants in this study can be found in Chapter Five, section 5.2) and why I have selected 'parents with learning disabilities' as my research topic. I outline my theoretical and methodological standpoints, including the importance of reflexivity for this study; these issues have inevitably shaped my research questions, which are stated briefly. The rest of the chapter examines (and deconstructs) the terminology used in the study, before ending with an outline of the thesis as a whole.

1.2 Why does this research focus on what professionals say?

Looking at what professionals say is important because they mediate between the welfare state and the recipients of the state's interest, care and control (Hugman, 1990). Decisions that professionals make have a huge impact on people's lives, particularly when it comes to deciding whether children should remain with their parents or be taken into care.

Though professionals make life-changing decisions we have little information about how they come to those decisions. How, for instance, do they balance theoretical knowledge with their life experiences?

Despite their great responsibilities, the voices of individual professional workers are rarely reported. The majority are women, taking on traditionally feminine mantle of 'caring'. Many are poorly paid and are in jobs with little career structure, especially those without recognised professional qualifications, such as support workers or advocates (Brown and Smith, 1992).

Therefore, my aim is to report and analyse the seldom heard views of a variety of professionals who work with parents with learning disabilities. My analysis will show the complexities of their task, for example, how they make sense of 'difference' in a group labelled 'disabled', how they

conceptualise parenting problems in this group, how they understand their position as 'professionals', and how they integrate professional and personal perspectives. This will lead to more general observations about the contemporary role of the 'professional', and their relationship to the welfare state and to their clients.

1.3 Why do research about parents with learning disabilities?

It would be almost impossible to estimate accurately how many parents with learning disabilities exist. The Government White Paper, 'Valuing People' (DoH, 2001) suggests a prevalence rate of people with mild/moderate learning disabilities within the general population of around 25 per 1000[1]. Developments in public policy such as 'Valuing People' with its emphasis on choice, rights, participation and independence for people with learning disabilities means that many of these young people grow up aspiring to the same achievements as their non-disabled peers, in terms of education, employment, relationships and parenthood. In some communities, such as the London Bangladeshi community, marriage and child-bearing may be more the norm, rather than exception for adults with learning disabilities (Hepper, 1999; O' Hara and Martin, 2002). It is therefore likely that many primary health care workers, such as midwives, health visitors and school nurses will come across and affect the lives of these parents and their children.

When it comes to the arena of Child Protection, it is likely that families where a parent has a learning disability will be over-represented. High

[1] Within the classifying discourse of mainstream psychology and psychiatry, terms such as 'mild', 'moderate' and 'severe' are used to indicate the 'degree' of learning disabilities, measured by psychometric tests. People with 'mild' or 'moderate' learning disabilities are assumed to be able to assume a greater or lesser degree of independence at least in self-care tasks and communication skills. These categories correspond to IQ scores below 70 and above 40 according to WHO and AAMR (American Association on Mental Retardation) classifications. The category of 'severe' learning disabilities would correspond to an IQ score below 40, and limited functional ability. Later chapters will deal more comprehensively with these classification systems, and argue for a sceptical, social constructionist critique of such terms.

rates of removal of children from the family home have been reported by international studies, perhaps of up to 40-60% (Accardo and Whitman, 1990; Mirfin-Veitch et al., 1999; Pixa-Ketner, 1998). Removal of a child will often be the culmination of protracted involvement of families where a parent has learning disabilities with social workers, family centre workers, family support workers, and the courts.

Moreover, working with families where the parents' activities are often the focus of scrutiny by agents of the welfare state, calls into question exactly how 'good-enough' parenting is defined. What exactly are the standards that parents with learning disabilities are so often judged to fall short of? What views of children and childhood are supported by various ideas about how parents should behave? How might being a good parent be linked to being intellectually able, and how might factors relating to class and gender interact with expectations about what a parent should be like? How do the goals of the state become translated into the requirements of the parenting task? Talking to professionals about the dilemmas they face in working with these parents raises more general questions about parenting, about children, and about the role of the state in monitoring and controlling families. These issues have relevance not only for those professionals, such as social workers, health visitors, midwives and therapists in specialist learning disabilities teams, but also for professionals and policy makers who design and implement the priorities of the welfare state relating to people with learning disabilities, parents and families.

1.4 Theoretical and methodological considerations

There is a strong tradition of psychological research into 'attitudes' as underlying cognitive structures which influence people's verbal responses and behaviour. However, this study owes its epistemological and methodological basis to an emerging strand in psychology which is critical of 'cognitivism' and 'attitudes' research (Edwards and Potter, 1992;

Hollway, 1989; Potter and Wetherell, 1987). Instead of assuming that something like 'a parent with learning disabilities' is a concept that we can objectively define and describe, about which we have relatively fixed and internally coherent 'attitudes' (these sorts of presumptions can be linked to the still prevailing 'positivist' or 'empiricist' emphasis in social and clinical psychology), I contend that such concepts are socially constructed in line with prevailing political, social and economic preoccupations (Burr 1995).

1.4.1 Preliminary remarks on discourse analysis

Discourse analysis is a method often associated with this investigation into how language users construct social reality, and which examines how, and to what ends concepts are constructed. A central tenet of discourse analysis is that 'talk is not transparent'. The researcher is not looking for ways of analysing texts in order to get to a reality beyond the talk itself, where the 'success' or 'outcomes' of interventions can be monitored. In a research interview, accounts are jointly constructed by the interviewer/researcher and interviewee with implications for practice and subjective experience, since discourses define possibilities for action and feeling. I develop a more detailed and critical description of discourse analysis, and how I employ it in this thesis in Chapter Four.

As theoretical and methodological approaches, social constructionism and discourse analysis are appealing to researchers interested in social change, as they invite the researcher and reader to adopt a critical stance towards taken-for-granted ways of understanding the social world, and allow us to imagine how things might be different.

In line with these considerations, the texts I analyse here are interviews structured around a few key questions relating to work with parents with learning disabilities. My analysis assumes that the participants are active creators of meaning who purposively make reference to wider understandings of disability, parenting, children and professionalism.

Moreover, in the interviews and analysis I reflect on my own contribution to the discussion and the underlying assumptions I bring to my encounter with the texts, an endeavour that falls under the rubric of **reflexivity**.

1.4.2 Reflexive practice: personal reflexivity

Reflexivity as a theoretical construct and as a research practice can be given a number of different meanings. Overall, this term refers to the way that the researcher reflects on her own contribution to the research process. From a social constructionist perspective, the activity of research is seen as the joint process of knowledge creation that the researcher embarks on with her participants. In this context, Sherrard (1991) stresses this responsibility of discourse analysts to examine explicitly their own 'moves' within the interview conversation, which are part of the construction of the discourse they are examining. We might call this **analytic reflexivity**. Willig (2001) also identifies **personal reflexivity** (see also Wilkinson, 1988) as distinct from **epistemological reflexivity**, where the former term refers to the way that the researcher acknowledges how her own agendas, experiences, motivations and political stance contribute to the way that the texts are analysed and interpreted. Far from being seen as obstacles to unearthing the 'facts' represented by the data, these personal factors can be valued as resources which enrich the research. Epistemological reflexivity is a linked process, but one which involves more an examination of our assumptions about what can be known and researched. This is what Potter and Wetherell (1992) call *'a critical examination of our own techniques of sense making'* . I revisit this practice at later stages in the thesis, but for now I will concentrate more on the place of personal reflexivity in this endeavour.

My standpoint in this research is inevitably influenced by my personal and professional experiences which have continued to evolve and be shaped, not only by events in my own life and in the social context in which I operate, but by the process of engaging in this research itself. Embarking

on a PhD has been characterised as an apprenticeship, or an induction into the values and practices of the academic community. But it can also been seen as an 'adventure' (Willig, 2001) or a journey (Salmon, 1992) where the researcher takes the risk of devoting a chunk of her life in order to address questions that have resonance for her on an individual level, whether linked to her personal life story or professional identity. As the thesis proceeds therefore, I engage in reflexive practice, not only by identifying how my own position, experiences and motivations have impacted on the structure and content of the research, but also by recording how the research, the process of addressing the relevant published literature, and engaging with my participants has impacted on me and my professional practice (see also Letherby. 2002).

These sorts of reflections (in italic script) are dispersed through the thesis, and are written in rather a different voice to the rest of the text.

I don't remember anything in my clinical training as a clinical psychologist in the early 1980s that prepared me for working with parents with learning disabilities. My first real encounter with such parents was in the context of supporting a couple at the point at which the local authority was applying for the removal of their daughter. From my perspective and that of my colleagues in special learning disability team the parents were two people struggling with their own health issues, with their traumatic emotional histories in institutions cut off from ordinary life opportunities, and with harassment from the local community. The local authority children and families social workers on the other hand saw their daughter as a sad and neglected little girl whose parents ignored her emotional needs, did not bother to buy her new clothes or shoes or get her to school on time. Meetings between professionals on each 'side' were long and acrimonious with the parents in the middle struggling to work out what was going on.

The usual clinical psychology tools that I had been asked to employ to assess these parents' 'needs' such as psychometric tests, inventories of their skills and competencies, analysis of their psycho-social histories and

mental health seemed somehow beside the point when it came to presenting evidence to the family court. Nor did the arguments of the parents' advocate about their rights and entitlement to services seem to have much impact. The couple's daughter was removed into local authority care.

This experience revealed to me how little I knew about the workings of child protection services and the concerns of workers in that sector. However, in connection to the court case my employer sent me on a course for expert witnesses and I did more reading about parents with learning disabilities, particularly the work of Sue McGaw in Cornwall and the Booths in Sheffield. I even went to visit Dr McGaw in Cornwall where she generously allowed me to observe the work of her 'Special Parenting Project'. Armed with this specialist knowledge I found myself in demand as an expert witness in child protection cases, where I was asked to assess parents with learning disabilities where the local authority was concerned about their care of their children.

I noticed increasing academic attention to parents with learning disabilities and special projects for parents with learning disabilities, like Sue McGaw's, springing up here and there, all of which I conscientiously referred to in my lengthy and thorough assessment reports. Nevertheless the parents that I came into connect with kept having their children removed into local authority care, against their wishes and with enormous emotional costs to all concerned. I did not feel my contribution was helping. Was I the only professional feeling so stumped? How did professionals from backgrounds in children and family work tackle these issues? Should I be doing something more, or something different? These were the sorts of questions that motivated the formulation of my research questions, and which kept bubbling under the surface during the process of conducting this research.

1.5 The research questions

My aim in this research is to examine how the discursive object, the 'parent with learning disabilities' is talked into being by professionals who encounter these parents, and how this construct occupies a particularly problematic discursive space. I contend that the ways in which professionals construct 'parents with learning disabilities' bring into sharper focus the contradictions and dilemmas within and between discourses relating to parenting, children, learning disabilities and the professional role. My claim is that a focus on parents with learning disabilities throws a penetrating and challenging light on received wisdom relating to parents and people with learning disabilities.

As a clinician myself, I am concerned with how various discourses afford different possibilities for practice. In this study I aim to reflect on the subject positions suggested by the discourses used by professionals, and how these present the participants with rights and responsibilities both within the discourse, and within their professional practice. I aim to show how discourses advocate and facilitate different courses of action that may have far reaching consequences for parents with learning disabilities and their children, for instance removing children from their parents or offering support to keep a family together.

Therefore, the research questions which I intend to examine can be summarised in the following manner:

Research question 1:

- How do professionals construct 'learning disabilities' when talking about parents with learning disabilities? What impact might ideas about parenting have on this process of construction?

Research question 2:

- How do professionals construct 'parenting' and 'the child' when talking about parents with learning disabilities? What impact might concepts of learning disabilities have on the process of construction?

Research question 3:

- How do professionals construct their own role when talking about parents with learning disabilities? What impact might concepts of learning disabilities have on the process of construction?

Research question 4:

- What possibilities for professionals' practice do these constructions open up or close down? What are the possibilities for resistance and the emergence of more positive and enabling constructions of parents with learning disabilities?

1.6 Terminology

A central theme of this research is that language is not neutrally descriptive of social reality. Therefore I need to explain and justify the terms that I use in my research. I need to make it clear why I use the terms 'learning disabilities', 'professionals' and 'parents', choosing these from amongst the available alternatives.

1.6.1 Learning disabilities

Terms which are currently in use as an alternative to 'learning disabilities' include 'learning difficulties', 'intellectual disabilities', 'mental retardation', amongst others. Other terms, which were commonplace twenty years ago, such as 'mental handicap', 'mental deficiency' and 'subnormality' have slipped out of use. Earlier and now obsolete terms include 'feeble-mindedness' and 'idiocy', As Sinason (1992) points out, 'no human group

has been forced to change its name so frequently (p.40)'. What is the reason for this confusing babble of terminology?

From a psychoanalytic perspective, Sinason argues that terms used to describe people who are different in ways which arouse primitive and unconscious anxieties become contaminated. The stigma that attaches to the person 'leaks out' into the descriptive term, so that a word like 'spastic', coined to describe the muscle contractions which characterise cerebral palsy, becomes a playground taunt. Sinason suggests that services coin new terms as part of a misguided attempt, at the level of omnipotent fantasy, to cancel out the pain, discrimination and stigma which is often part of the lives of disabled people. Armstrong (2002: 453), examining histories of special education in England and France, has also expressed scepticism about the likelihood that terminology used to identify disabled people can ever be established as 'neutral':

> *It is interesting to reflect on the possible constructions in future periods of the contemporary language of 'special needs', and labels such as 'severe', or 'moderate', 'learning difficulties', 'EBD', and 'autistic' in England, or 'handicape' 'leger', 'moyen' or 'profond' in France.*

I have chosen the term 'learning disabilities' because of the shades of meaning in the term that relate to the institutional context. I do not think it is a particularly useful term; nor am I making any claims for its 'neutrality' or self-explanatory power. Indeed, I would not be surprised if it falls out of fashion in a few years time. However, it is the term that has been most widely adopted by specialist services for adults within the public sector in the UK and it has a history and resonance within that context ('mental retardation' and 'intellectual disability/impairment' are terms with equivalent prevalence in the USA and Australia, respectively). It is the term used in the Government White Paper 'Valuing People' (Department of Health, 2001), where it appears without comment, though rather bafflingly both in the plural and the singular ('a new strategy for learning disability', 'people with learning disabilities', 'learning disability services', 'parents with a learning disability').

The term that has been favoured by self-advocacy groups such as People First UK is 'learning difficulties'. Self-advocates who promote this term have commented that it distinguishes them from people with physical disabilities (Goodley, 2000). 'Learning difficulties' is perhaps a more 'politically correct' term than 'learning disabilities' in some quarters, and is used by researchers, activists and paid advocacy workers to signal support for the goals of self-advocates, and a theoretical perspective which emphasises human rights and the social dimension of disability. However, an institutional constraint to this term being more widely adopted, and another reason why I have not used this term in my research, is that 'learning difficulties' is used in educational settings to categorise and define children with problems which create barriers to effective learning in school, including diagnoses such as dyslexia and ADHD.

In this section I have explained why I chose 'learning disabilities' over other descriptive terms. I have not attempted to define the term, in other words, to unpack its meaning. One of the central research questions is how people construct meaning for this term, and this endeavour has a history and epistemology which I examine in later chapters.

1.6.2 Parents

I have chosen the term 'parents', rather than 'mothers and fathers', in line with the majority of published research in this area. Specialist services have also been set up to work with 'parents' with learning disabilities (Tymchuk and Andron, 1992; Campion, 1996; McGaw, 1998; Woodhouse, 2001). At face value, 'parenting' could be said to be the activities that mothers and fathers undertake in bringing up their children.

However, using this term may gloss over some more complex issues. First, although a number of researchers refer to 'parents' with learning

disabilities in the titles of their papers, closer inspection reveals that they are talking exclusively about mothers (Feldman, 1998), with the men in their lives apparently off the radar (Booth and Booth, 2002). Moreover, it is not always clear whether the fathers in these studies have learning disabilities, and there is little consideration of the specific issues faced by fathers with learning disabilities and the people who support them. The role played by fathers with learning disabilities also seems to attract less notice when parents with learning disabilities come into contact with the courts. Field and Sanchez (1990) note that *'the cases involving parenting by persons with retardation almost invariably involve women'* (p.22). Therefore, in some contexts, we can conclude that 'parent' means 'mother'.

The second point is related to the first. If by 'parent' you mean 'mother', why not come out and say so, instead of using a supposedly 'gender-neutral' term which suggests that childcare tasks are shared equally between men and women? The term 'parent' obscures the fact that there are very different expectations of the kinds of input provided by mothers and fathers. Mothers are generally expected take prime responsibility for bringing up children with fathers maintaining an auxiliary role.

In this research, however, I examine how professionals talk about both mothers and fathers with learning disabilities. Inevitably, data relating to childcare and the role of the caring professions will contain gendered discourses, including constructions of paternal and maternal identity. However, my focus is more on how their disability is understood by practitioners than their gendered identities as mothers or fathers. I use the term 'parents' because I contend that mothers and fathers with learning disabilities have important characteristics in common, in terms of their experiences as disabled people and the processes of exclusion and restriction that they encounter. In a similar vein, Qvortrup (1994) argues that in order to create a new sociology of childhood researchers need to take as their starting point 'childhood' as a structural category, comparable to other structural categories in society, even if this means overlooking the

different childhoods which children inhabit, influenced by factors such as gender, class and location. Using 'parents with learning disabilities' as my category for analysis, I can investigate participants' explicit and implicit comparisons with other parents, highlighting in which ways disability becomes a marker for difference.

1.6.3 Professionals

The participants in this research come from a wide variety of occupational backgrounds. They are health visitors, social workers, psychologists, managers, advocacy workers, and support workers. Therefore, there is wide variation among the participants in terms of power and authority, training, autonomy. From a sociological perspective, health visitors, social workers and psychologists meet some, if not all of the 'traits' which characterise the archetypal professions of medicine and law, such as skills based on theoretical knowledge, provision of training, testing of the competence of members, autonomous organisation, adherence to a professional code of conduct and an ethos of altruistic service. Support workers and advocacy workers might have little formal training, and work under close supervision, without recourse to a theoretically derived skills base.

However, any definition of 'professionals' based on a list of attributes may be criticised as idealised, and referring to an arbitrary group of traits, often selected by someone who is arguing for the inclusion of a particular occupational group into the pantheon of 'professionalism' (Johnson, 1972). What the participants in this study have in common is that they are all 'professional' in the sense of being paid to do a job which comes under the rubric of 'caring'. Their work centres on a commitment to improve the lives of their clients. There is a suggestion that their work is vocational and based around an altruistic willingness to selflessly dedicate one's time to others (Abbott and Wallace, 1990).

Hugman (1991) argues that 'caring work' is based on personal relationships and social skills. 'Caring' is also gendered work, in that traditionally, caring for the young, old, sick or needy, has been work undertaken by women, and seen as demanding 'feminine' skills. Social work, midwifery and health visiting as salaried occupations developed in the nineteenth century, as extensions of the charitable work, visiting the poor, and attendance at childbirth routinely undertaken by women at that time (Abbott and Wallace, 1990).

Another important characteristic that the 'professionals' who took part in this study share, is that they are all linked to bureaucratic organisations, which are bound, to a greater or lesser degree, to the ideologies and legislative demands of the state. The health visitors and social workers may have the closest relationships with the state. Health visitors are charged with a key surveillance role, visiting all families with children under five to promote 'normal' child development (Abbott and Sapsford, 1990). Social workers also allocate state resources and have a statutory role to remove children from families that fail them according to the state's criteria. Advocacy workers may take an overtly oppositional stance to the state on the behalf of their clients, but even they have to work within legislative constraints and through an individualising and classifying system that defines who their clients are.

1.6.4 Concluding remarks about terminology

As the foregoing discussion of 'learning disabilities', 'parents' and 'professionals' illustrates, the relationship between terminology and social reality is complex. None of these terms can be said to be simply and umambiguously descriptive of a state of affairs, though we often take for granted that they are. Selecting a particular term over another may suggest a certain political stance, or a set of allegiances, or a relationship to specific historical or contemporary discourses. My interpretation of some of the meanings of these terms may be contested, I am sure.

However, I hope I have been able to justify my own use of these terms and explain how my choice makes sense within the context of my research questions. I have also introduced some issues relating to the social construction of disabled identities, and of the role of parents, as well as the importance of issues of power and gender, which I will explore at greater length in later chapters.

1.7 Outline of the rest of the study

Chapter Two provides some background context to the study, by describing the public services which are accessed by parents with learning disabilities. In Chapter Three I review a wide range of literature relating to these parents. The survey is broadly historical, looking at how these parents have been constructed in different eras and with relation to different developments in understandings of disabled people and different models of services for people with learning disabilities.

Chapter Four describes the theoretical and epistemological underpinnings of the study. I explain the social constructionist stance that informs this research and link it to discourse analysis as a method. Discourse analysis has become more widely used within social sciences in recent years and has coalesced from its origins in ethnography, conversation analysis, sociolinguistics, and the work of Goffman, Sacks and Foucault into different traditions (Wetherell et al., 2001). I describe my integrative approach to discourse analysis and break down the method into a number of stages. I also examine different understandings of the concept of 'reflexivity' and suggest how they may impact on the process of conducting a research project of this kind.

In Chapter Five I describe how the research took place, defining the setting, the participants, and the interview and transcription methods.

The next six chapters use extracts from my interview data to examine how the participants in this study construct discourses relating to learning disabilities, to parenting and childhood and to the professional role. In Chapter Six I focus on discourses relating to learning disabilities both as a deviation from normal expectations of personhood, whereas in Chapter Seven I examine ways in which this negative, essentialising view of 'learning disability' can be resisted. Chapter Eight and Chapter Nine consider discourses relating to parenting and children in which consideration of responsibilities and risk come to the fore. My interest in looking at how professionals position themselves with relation to parents with learning disabilities informs all the data chapters, but becomes the focus of Chapter Ten, where I emphasis the difficulties and dilemmas both intrinsic to the professional role, and evoked by the specific nature of work with parents with learning disabilities. Chapter Eleven examines the possibilities for professionals to confront and resist the constraints they experience in their work with these parents.

Chapter Twelve is the final chapter in this study and I return to the research questions posed in the Introduction and summarise the findings of the study with relation to these initial questions. I also draw together a few key themes that run through the analysis of the data in a more general way. I will summarise the possibilities for action that the study participants refer to and examine their consequences for the lives of parents with learning disabilities and their children. This chapter also contains a critical reflection on the study itself.

Chapter Two: Outline of Services

2.1 Introduction to Chapter Two

In this short chapter I describe the services settings where the professionals who participated in this study were likely to come across parents with learning disabilities. I also touch on the historical development of services and the legislative framework that has underpinned this development. I dwell in more detail on the increasing preoccupation with 'child protection' issues which characterises contemporary children and families services and the impact that this is having on the conduct of family life and on the practitioners who are charged with addressing the welfare of children. I have already alluded to the finding that parents with learning disabilities are more likely than other parents to fall foul of child welfare services (see for example Goodinge, 2000 and McConnell and Llewellyn 2002. Studies looking at this issue are discussed in the literature review chapter, Section 3.4). My examination of current debates around child protection goes some way to explain how the climate of fear, caution and bureacratisation of professional child care work provides the setting for heightened professional anxiety when dealing with parents with learning disabilities.

2.2 'Mainstream' services for parents and children

In common with other parents, those with learning disabilities and their children come within the purview of a variety of health and social services professionals, whose remit is the wellbeing of parents and children in

general. Health visitors, who these days are employed by Primary Care Trusts, have responsibilities to monitor and promote the health of all children under five years old. Their responsibilities include immunisation, developmental check-ups, health promotion and monitoring of child-care practices. Based in GP surgeries, or Primary Health Care Centres, they hold clinics to which parents are encouraged to bring their children, and also visit children in their own homes. Parents are not legally required to take up their service, but there is a strong 'moral' expectation that they will do so (Mayall, 1993).

As a profession, health visitors are likely to emphasise their role in providing support and information to parents, though there is a tension between the health promotion and surveillance aspects of their role (Abbott and Wallace, 1990; Appleton, 1996; Peckover, 2002). Increasingly, health visitors are meant to be on the alert for instances of neglect and abuse in the home (Crisp and Lister, 2004).

Working with children and families has always been a core part of the social work profession, though increasing specialisation has lead to the establishment of social work teams which work with other client groups; older adults, children with disabilities, adults with physical or learning disabilities, adults with mental health problems.

Compared to health visitors, social workers have more clearly defined statutory powers when it comes to intervening in the family setting. Locally based Children and Family social work teams have responsibility for assessing, and providing services and support to children 'in need' as defined by the **Children Act, 1989** (namely those whose health and development would be likely to be impaired without additional intervention). The same act emphasised the requirement of social workers to act 'in partnership' with parents, but also set out the legislative framework for the removal into local authority care of children who are suffering or are likely to suffer 'significant harm' due to parental abuse or neglect.

The rise of New Labour in the late 1990s has seen the increasingly politicisation of family affairs and children's lives, as creating a better educated and more disciplined workforce, and the alleviation of child poverty have become central planks of government policy (Little et al., 2003). The Green Paper **Every Child Matters** and the **Children Act 2004** seek to improve services to children and prevent a recurrence of the circumstances that led to the death of Victoria Climbie investigated in the influential Laming report. The Act recommends bringing together education, health and social welfare services for children in Children's Trusts, and more contentiously expands the surveillance capability of the state by establishing an electronic database containing information on all children in England and Wales (Munro, 2005

2.3 Contemporary debates on child protection

As Ayre (2001) has pointed out, at the same time that the child protection services in England and Wales have expanded and assumed every higher levels of elaboration and visibility, requiring ever greater input of resources, the child care workers who are charged with implementing these services can count on little public confidence or respect.

Other commentators have offered explanations for why the issue of protecting children from abuse has come to occupy such a central and hegemonic position in social welfare (Hendrik, 2003; Jenks, 1996; Parton et al., 1997; Parton, 1996, 1998; Pilcher and Wragg, 1996). First, the term, 'child abuse' has broadened from the original concept of 'battered baby syndrome' to include neglect, physical, emotional and sexual abuse (Parton, 1998; Thorpe 1995). Powered by high-profile child abuse investigations and campaigns co-ordinated by state and voluntary sector agencies, public, professional and political awareness of abuse is now at an all time high. Not only has there been a dramatic increase in child abuse allegations requiring investigation (Parton et al., 1997; Scourfield, 2000), but this has happened in a changing politico-economic climate.

Economic inequalities have become more pronounced in the last twenty years, leaving a growing group of marginalised and socially excluded sections of the population, while social service departments have experienced constant cut-backs, restructurings, and recruitment crises (Welbourne, 2000: 16). Faced with increased demand and reduced resources to meet this, child welfare agencies are forced to prioritise and to do so on the basis of risk, even when, as research by Spratt (2001) indicates, they accept the importance of orientating their service towards the provision of support and meeting children's and families' needs: '*The findings [from the research] lend support to the hypothesis that the first priority of social workers is to manage risk*' (Spratt, 2001).

On the one hand expectations of workers with children and their families are perhaps unreasonably high; they are charged with the protection of children and are expected to be able to work towards the practically impossible task of actually eliminating risks facing children (Dartington, 1995, quoted in Spratt, 2001: 950). On the other hand public support and confidence in social workers in particular is low.

The loss of public confidence in social care professionals is linked to what Hendrik (2003) and Parton (1996; 1998) in particular, theorise as the break-up of the 'post-war consensus' on welfare, crime and the economy in the 1970s and 1980s. They argue that the previous period was marked by the optimistic expansion of social welfare service, stimulated by the belief that the professional agents of the state, backed up by social scientific knowledge could effectively tackle social problems.

> *As a political rationality, 'welfarism' was structured by the wish to encourage national growth and well-being though the promotion of social responsibility and the mutuality of social risk, and was premised on notions of social solidarity* (Parton, 1998: 12).

This dominant discourse of 'welfarism' and the position of social care workers within it have been undermined by a series of social and political developments. Parton (1998) in particular identifies the impact of the

women's movement from the 1960s on the recognition of violence within the family, with the resultant disaggregation of the interests of different family members. Furthermore, the development of other 'rights' movements and the civil liberties critique of state intervention queried the social control aspects of welfare intervention, and the lack of fairness in the distribution of welfare resources. These arguments developed from the political left, but were extended and given a new spin within the Thatcherite 'project' (1979-1997) which sought to withdraw state intervention from the private sphere of the family and curb the influence of unbiddable local authorities and professional interests (Pilcher and Wragg, 1996).

More specifically, child welfare professionals still cannot escape the fallout from the 'moral panic' and public disillusionment following a number of child abuse scandals from the late 1970s. On the one hand the public inquiries between 1980-1987 into the deaths of children who died following abuse and neglect at the hands of their parents or step-parents, Jasmine Beckford, Tyra Hendley, Kimberley Carlile, accused social workers of minimising risks and failing to protect children. On the other hand the Cleveland Inquiry of 1988 condemned social workers and medical workers (typecast as 'politically correct', anti-'common sense' or 'ultra-feminist') of undermining 'normal' family life as an exercise in 'empire building' and spurious advocacy of 'children's rights' (Kitzinger, 1996). Condemnation from official channels was augmented by sensational press coverage which fanned the flames of vilification of social workers (Ayre, 2001; also see Mendes, 2000, for a consideration of similar processes in Australia during this period). The stage was set for a 'culture of blame' and scapegoating of individual workers or teams (Reder and Duncan, 1999). These dramas of recrimination and blame have continued, with one outcome of the inquiry into the death of Victoria Climbie being the inclusion of the frontline social worker on a register of those who present a danger to children. Even parents with learning disabilities can be portrayed as guardians of traditional family values by the Daily Mail when pitted against interfering social workers (Barton, 2005). In a series of

articles published in 2005, journalists raised the spectre of totalitarianism by referring to Essex social services as 'thought police', and describing the plan to remove the children into local authority care as 'social engineering gone mad'[1].

The Children Act of 1989 was to some extent a response to these contradictory constructions of child care workers – both as 'naively hands-off' and 'interventionist bullies'. In retrospect, commentators including Pilcher and Wagg (1996), Parton (1996), and Hendrick (2003) have evaluated this act in terms of how it managed to strike a balance between upholding the institution of the family as the best place for children to grow up, and strengthening social workers' capacity to intervene where, in the language of the Act, children are deemed 'likely' to suffer 'significant harm'. They concluded that the legacy of the Children Act as it has been played out in the last two decades, has been

> *an overt emphasis on the propriety of the closed family bound by traditional patriarchal and parental virtues, in which the rights and even the welfare of children were secondary considerations* (Hendrick 2003: 42).

Intrusive state intervention is downplayed through the language of 'partnership' and 'working together' and the accountability of social workers is underlined by a clearer role for the police and the legal process. Parton (1996) criticises the dominance of the 'legal gaze' over family work and in determining what constitutes 'significant harm', which he feels has fostered an overriding concern with child protection issues at the expense of child welfare and family support (see also Thorpe, 1995). He deplores the ensuing preoccupation with accountability and insuring against public inquiry which he sees as a consequence of the procedural and legalistic mentality reflected in the Act.

[1] Thus hinting at the lurking presence of the Daily Mail bete noir of 'political correctness gone mad'.

In order to uphold the balance between state intervention and family autonomy, Parton (1996) and Hendrick (2003) have argued that the Children Act has recourse to the 'medical model' of abusive families. A sociological perspective on child abuse might focus on socially impoverished environments as creating the preconditions for abuse, or even go further to identify structural inequalities within the family and within society as a whole as the true agents of abuse of children (Corby, 1989; Hendrik, 1990). An individual 'medical model' of abuse largely ignores the social context of abuse towards children to focus attention on specific inadequate parents. A few families, because of their intrinsic nature and shortcomings are pathologized as abusive. The task of social workers and others is to identify these families and protect their children.

> *The public lessons drawn from scandals of child abuse do not, today, point to the need for the education and moralization of a whole class of society, a benighted portion of the social body whose ineptitude or indifference threatens the wellbeing of the nation. The family that has failed to grasp its therapeutic and pedagogic obligations appears today less as a sign of the amorality or ignorance of the poor than as consequence of the individual psychopathology of a tiny minority of individuals or couples, explicable in terms of their personal characteristics or family history, and requiring criminal sanction or psychiatric attention* (Rose 1999: 206).

Inevitably the balance between ensuring the privacy of family life and ensuring the protection of those deemed vulnerable and in need of protection will be subject to constant adjustments and modifications, as it is constructed around a central tension and paradox. As concern about risk mounts ever higher, there can be less tolerance of the idea that any child might 'slip through the net' and be exposed to harm.

The 2004 Children Act creates new categories of risk through the proposed establishment of a national database holding information on children and families from a variety of sources; doctors, schools, community health and social care staff. Risk becomes a function of an accumulation of concerns from all these sources, even when the individual infractions of expected standards of parental behaviour are relatively trivial

and subjectively defined (Munro, 2005). The information database and the growth of 'Children's Centres', bases for health, education and social services for children located within school grounds, extend of the reach and penetration of systems of surveillance in a all-encompassing web of 'joined-up' professional networks (Allen, 2003) Response to the Act has raised concerns that professionals overriding confidentiality to flag up relatively minor worries about risks to children may have negative consequences, including less time for professionals to investigate potentially serious cases; greater professional defensiveness; and a further breakdown in trust between professionals, children and parents (Silverman, 2004; Munro, 2005).

2.4 Specialist learning disability services

The starting point for the development of community services for people with learning disabilities was the Government Circular, **Better Services for the Mentally Handicapped** (HMSO, 1971) which was published at a time when large mental handicap hospitals provided 'total care' for thousands of people unable to remain with their families (Whitehead, 1992). Local authority services for people with learning disabilities expanded rapidly during the 1970s, including residential provision and day centres. The confluence of the new, human rights based service philosophy of 'Normalisation' (described in more detail in my literature review) and the economic imperatives of the Thatcherite Community Care[2] initiative led to the emptying of the mental handicap hospitals during the 1980s (Brown and Smith, 1992) and the growth of multi-disciplinary learning disability community teams of health workers including specialist community nurses, speech and language therapists, psychologists, and physiotherapists.

[2] The development of 'Community Care' during the 1980s was motivated by a number of factors. Though one justification was the need for an alternative to institutional provision which as a model of service delivery was increasingly seen as depersonalising and inhumane, impetus also came from the opportunity to release the huge capital value of old hospital sites into the public purse (Whitehead, 1992).

In addition the Thatcherite laissez-faire market ideology opposed the direct provision of service by what were essentially state monopolies, and argued that allowing a variety of service providers to compete in the market place would promote quality and consumer choice (Griffiths, 1988; Rapley and Ridgway, 1998).

It was against this background that the 1990 **NHS and Community Care Act** (and the further guidance in the policy paper, Social Care for Adults with Learning Disabilities (Mental Handicap), Department of Health, 1992) set out regulations for the provision of community care services, such as accommodation and welfare to people over the age of 18, 'in need of care and attention' by reason of their disability. Local authorities could buy these services from non-statutory agencies, for instance agencies providing unqualified 'support workers', which quickly began to proliferate in the 'mixed economy of care' (Griffiths, 1988). Social workers in local authority learning disability teams became recreated as 'care managers'; 'care' was reconceptualised as something to be 'packaged' and 'managed' as opposed to being bound up with an ongoing supportive relationship in the traditional (if idealised) mode of social work intervention (Rapley and Ridgway, 1998; Katbamna et al., 2004).

The aspirations of the 2001 learning disability White Paper, Valuing People (Department of Health, 2001) were to usher in a new era of service provision for people with learning disabilities, based on the principles of civil rights, independence, choice and inclusion. The creation of local Learning Disability Partnership Boards has formalised the participation of people with learning disabilities and there is emphasis on developing advocacy services and client led 'person centred plans'. In line with the push towards 'joined up' welfare provision promoted by New Labour (Allen, 2003), Valuing People has required health and social services professionals working with people with learning disabilities to forge closer links in 'integrated' teams.

Nevertheless, Valuing People has been criticised for focusing on service systems and failing to legislate against the ongoing exclusion of people with learning disabilities from employment, education and leisure opportunities. This is despite the adoption of the **Human Rights Act** (1998) which enables people with learning disabilities to protest against violations of their human rights in the UK courts (Hughes and Combes, 2001). Valuing People has been welcomed for re-emphasising the need for services to operationalize key values of respect, choice and inclusion for people with learning disabilities. However, questions remain as to how far people with learning disabilities are being put at the centre of the decision-making process, either at the organisational or individual level (Fyson and Ward, 2004).

Chapter Three: Review of Literature

3.1 Overview of literature review

In this chapter I examine how the 'parent with learning disability' has been created as a social problem and how a preoccupation with the reproduction of people with learning disabilities has shaped development of services from large segregated institutions of the Nineteenth Century to contemporary prenatal screening campaigns. This historical overview does not characterise responses to these parents as progressing inevitably towards greater tolerance, understanding and acceptance. Rather, I identify key shifts in how these parents have been understood, classified and controlled within a historical narrative marked by false starts, contradictions and sometimes unexpected consequences (Armstrong, 2002).

Services established at the turn of the 20th century inspired by eugenic ideologies were transformed by the dissemination from the late 1970s of the principle of 'Normalisation', a human rights based ideology which led to the development of the 'ordinary life' model in services for people with learning disabilities. Despite its progressive credentials, I question the opportunities offered by this movement for parents with learning disabilities. A frequent criticism of Normalisation in practice is that it put the onus on marginalised people to 'fit in' with existing social

arrangements. Psychologists and other human service professionals responded by developing and fine tuning a range of technologies designed to bring the socially 'unacceptable' behaviours of marginalised people into line with dominant cultural norms. Related to this development was the propagation of a number of 'parent training programmes' directed at parents with learning disabilities. I evaluate the impact of this literature and practice on the position of parents with learning disabilities. I also look critically at the 'social model of disability' as a way of understanding the position of these parents, and as presenting possible opportunities for resisting oppressive and discriminatory practices.

3.2 Eugenics: theory and practice

The story of the care and control of men, and more especially, women with learning disabilities (Brady, 2001) over the last hundred years or so, reflects an ongoing concern with issues of sexuality and reproduction (Kempton and Khan, 1992; Woodhill, 1992). In this section I trace the development of the eugenic social movement, linked to particular social and economic developments, and identify how the idea of people with learning disabilities giving birth was construed as a social problem. I also investigate how eugenic principles were applied to the treatment of people with learning disabilities through various techniques of control including psychometric assessment; study of family lineages; sterilisation and segregation within institutions. In particular, I look at the development of institutionalisation as the model for services for people with learning disabilities in the UK and examine the ways of thinking about parents with learning disabilities that were supported by institutionalised practices. A final passage evaluates the impact of developments in clinical genetics in recreating a climate favourable to eugenic preoccupations with population control.

In the early 20th century, social scientists and public servants were greatly influenced by the spread of eugenics theory and social activism. The term **eugenics** was coined in 1883 by Francis Galton, who was interested in developing mathematically grounded theories of heredity. This approach has a core belief in the heritability of positive and negative human traits of talent and character One result was an urge to protect positive community characteristics through selective breeding, and the restriction of the fertility of people with learning disabilities and other 'defectives'. In the first part of the 20th century this formulation was widely accepted as an urgent social truth by people from disparate parts of the political spectrum (Paul, 1995; Park and Radford, 1998). These years were marked by reordering of social relations and the growth of the labour movement in Britain, economic fluctuations leading to worldwide economic depression in the 1930s, and widespread social anxieties linked to the perceived growth of an expanding underclass, comprising vagrants, the feebleminded, criminals and immigrants. In particular the feebleminded were not only seen to be the cause of multifarious social ills including prostitution, pauperism and crime, they were also assumed to be prolific and thoughtless breeders, to the extent that they and their offspring threatened to 'swamp' the healthy portion of the population (Woodhill, 1992; O'Brien, 1999).

Even more frightening, proponents of eugenics emphasised the hidden nature of mental defect (Paul, 1995). Though they were often able to pass as 'normal', mental defectives' true limitations and ability to breed social undesirables could be exposed by experts able to exploit the technology offered by the new psychometric tests popularised by Goddard in the USA. An emerging corps of (predominantly female) social science researchers and social workers could also detect the malevolent impact of bad heredity through their expertise in assembling pedigrees and family histories of cacogenic families, inspired by Goddard's hugely influential book, *The Kallikak Family* (1912). Thus, eugenics, inasmuch as it stimulated the development of psychometric testing and segregation in institutions, also provided the impetus for the practitioners to invent

mentally deficient men and women as docile bodies (Foucault, 1977), available for testing, categorisation, surgical excision of their ability to procreate, and institutional placement.

In the United States the eugenic movement achieved a great deal in terms of state legislation, and public visibility. This success was related the intensity of social disturbance at the beginning of the 20th century, and responses to mass immigration from Europe, and the internal migration of rural poor black people to urban centres, as well as the ability of prominent eugenic activists to secure funding from wealthy philanthropists. The more extreme eugenic goal of enforcing involuntary sterilisation of carriers of defective genes became a reality when local interests managed to pass sterilisation statutes through state legislatures. At first these statutes proved vulnerable to repeal, until the Buck v Bell ruling in 1927 confirmed judicial support for involuntary sterilisation. Sterilisation became increasingly '*routine, ordinary and hence self-regulatory*' (Trent, 1994: 224), continuing as a matter of course for decades, until the 1970s, by which time 60,000 individuals had been sterilised involuntary (Reilly, 1991).

However, by the 1930's geneticists widely recognised that the relationship between genes and undesirable traits was more complex. If mental defects were attributable to recessive genes, sterilisation would not be a feasible method of eliminating feeblemindedness. Nevertheless, involuntary sterilisation was still pursued enthusiastically, on the grounds that the mentally defective could never satisfactorily discharge the responsibilities of child rearing. Reilly (1991: 94) concluded that state officials

> *became less concerned with preventing the birth of children with genetic defects and more concerned with preventing parenthood in those individuals who were thought to be unable care for children.*

In Britain, the call for imposition of involuntary sterilisation was more muted. Opposition came from Parliament, from the Catholic lobby and

from the labour movement, which interpreted the rhetoric of eugenics as an attack on the power and authority of the working class (Paul, 1995). Segregation of the mentally defective in institutions was seen as the preferred means of attaining eugenic results[1].

However, eugenic ideology provided a considerable spur to the expansion of institutionalisation in the early 20th century. Institutions achieved eugenic results by segregating the mentally defective from the normal population, decreasing the risk that feebleminded females would interbreed with and debase the healthy stock, and also by enforcing strict segregation of the sexes within the institution. Moreover, public demand for institutional places increased as the rhetoric of the 'menace of the feebleminded' permeated public consciousness and increased the stigma of having a mentally defective family member.

The farm colony offered a solution to the spiralling costs of expanding institutions by setting up self-sufficient agricultural and manufacturing enterprises using labour from among the inmates. Colonies established in the 1920's and 1930's, such as that at Langdon in Devon, rigidly separated the sexes in buildings as well as territories (Radford, 1991). Under the impetus of the Mental Deficiency Act of 1913, which placed the onus on local authorities to quantify and provide for various types of mental defectives within their jurisdictions, institutional places expanded. By 1939 the Board of Control for Mental Deficiency Act reported bed capacity for 46,000 in certified institutions in the UK, compared with a little over 2,000 some 24 years before.

[1] The history of the institutionalisation of people with learning disabilities certainly predates the eugenic movement. Special institutions for 'idiots' variously named 'schools', 'asylums' or 'homes' existed from the first half of the 19th century in Britain, and by 1874, 1600 idiots were placed in eleven institutions (Thomson, 1992). The underlying ideology of these institutions was educational, inspired by the teachings and writings of the French doctor, Edouard Seguin, who claimed his physiological method achieved great improvements in the abilities of idiots (Seguin, 1866).

The proponents of eugenic policies engendered something like a 'moral panic' in the first decades of the 20th century in which people with learning disabilities became constructed as a danger to society, the source of many social ills, and dehumanised in the process (O'Brien, 1999). The expansion of institutions was given impetus by this ideology, which also engendered a bureaucratic machinery for local authorities to admit people with learning disabilities into institutions. Institutionalisation of people with learning disabilities became a taken-for-granted, routinised (Trent 1994) procedure even after the impact of eugenic ideas had waned. In contrast to the early 20th century model of the menacing, licentious, fecund (female) feebleminded of the eugenic movement, the institution created an 'inmate' who was hidden away, shameful, passive and officially sexless. As institutions admitted younger children and even infants, the prototypical 'mental defective' became an institutionalised child. Institutional language extended inmates' childhood indefinitely, labelling them 'boys and girls' with the more profoundly disabled known as 'babies', even in adulthood.

The eugenics movement lost its position in the first rank of academic endeavour after the 1930s. It was at least temporarily discredited by its association with the racist policies which were transformed into the genocide by the Nazis, not only of 'defective races', but also of people with learning disabilities and mental illnesses. Nevertheless, echoes of eugenicist concerns can be identified in academic research and public policy in the last fifty years. Epidemiological studies undertaken between the 1950s and 1980s (Brandon, 1957; Reed and Reed, 1965; Gillberg and Geijer-Karlsson, 1983; Accardo and Whitman, 1990) display a concern with the heritability of learning disabilities and the cognitive development of children of adults with learning disabilities. Reed and Reed's conclusions echoed the claims of earlier proponents of eugenics in their assumption that it would be possible and desirable to reduce the number of 'the retarded' through controlling their fertility:

> *When voluntary sterilization for the retarded becomes a part of the culture of the United States, we should expect a decrease of about*

> *50 percent per generation in the number of retarded* (Reed and Reed 1965: 77-78).

Such studies of heritability raise many methodological questions, not least relating to the definition of 'learning disabilities', and few have been undertaken in recent years. However, debates about the ethics of sterilisation of men and women with learning disabilities continue in the courts, when carers, usually parents, apply to have their sons or daughters with learning disabilities sterilised (Brady, 2001). In these cases, arguments rehearsed are not about the 'tainting' of the national stock, but about the inability of the woman to deal with any aspect of reproductive functioning; about the distress that a woman with learning disabilities would experience to go through with a pregnancy, and inevitable separation from her child (Baum, 1993); or about the poor quality of life that would be the fate of the child.

In some quarters, claims made by scientists and clinicians about the benefits of the advances in applied genetics, particularly antenatal screening for foetal disorders such as Down's syndrome, have been characterised as eugenic or neo-eugenic, especially by disability activists (Paul, 1995; Shakespeare, 1998). Bailey (1996) has pointed out that in common with the early 20th century eugenic movement, the application of new screening technology allows for the eugenic aim of 'improving the quality of the population by eliminating supposedly bad characteristics' without the need for coercive government intervention. Shakespeare (1998) and Cunningham-Burley and Kerr (1998) have noted the 'ritual disclaimers of eugenic intent' but criticise genetic scientists and clinicians for ill-advisedly down-playing the social impact and underlying cost-benefit rationale of pre-natal screening.

Of course, the social and political climate in the last twenty years has created a very different context for the expansion of genetic and prenatal screening technologies. Political principles adopted both by the Conservatives and New Labour emphasise consumer choice, individual

advancement, and discourage dependence on public assistance. Arguments that uncritically promote prenatal testing and removal of the 'defective' foetus, construct people with disabilities as unwanted and a burden on society (Alderson, 2001b; Stehlik, 2001), unable to assume socially valued roles, particularly as parents themselves. In this climate, attitudes towards parenting by people with learning disabilities likely to remain negative (Aunos and Feldman, 2002).

3.3 Normalisation and the ordinary life model: implications for parents with learning disabilities

As I have shown, eugenic theories and policies were explicitly directed at limiting opportunities for people with learning disabilities to have children. By contrast, the principle of **Normalisation**, the 'Ordinary Life' model and the service developments they inspired appear to challenge the exclusion of people with learning disabilities from roles and activities taken for granted by non-disabled people, such as marriage and parenthood. However, despite having a major impact on thinking and design of learning disabilities services in the UK, Normalisation theory and practice have achieved only a limited impact in terms of enhancing the acceptability of parenthood for learning disabled adults.

When considering the impact of Normalisation on the sexual options of people with learning disabilities, Brown (1994) lamented the failure of Normalisation to offer more control and self-determination to people with learning disabilities when it comes to their sexual lives.

> *The recognition of abstract rights has failed to break through the barriers of prejudice and isolation and to create real opportunities for people with learning disabilities to live different kinds of partnerships and family groups or to enjoy a range of sexual relationships, contacts and activities* (Brown, 1994: 123).

After a brief review of the Normalisation principle, I link this failure both to limitations in the application of the principle, and also to difficulties and contradictions within the concept itself. Finally, I use this review of the literature relating to Normalisation as a springboard to reflect on my own experiences of exposure to Normalisation, and my own perceptions of its impacts.

'Normalisation' is the term given to theories originating in Scandinavia in the 1970s which advocated that people with learning disabilities have the right to access 'normal' and usual patterns of everyday life, including in housing, employment, healthcare, and relationships (Bank-Mikkelsen, 1980; Nirje, 1976).

Around the same time in the UK, concern with the institutional care model was mounting, fuelled by public condemnation about abusive practices that came to light at South Ockenden, Ely, Farleigh, and Whittingham hospitals, and given a theoretical push by deviancy sociologists inspired by Goffman (1961) and a political impetus by growing civil rights movements. In pragmatic terms, the expansion of local authority services in the 1970s and economic arguments for 'community care' also contributed to the receptiveness of learning disabilities professionals and policy makers to the Normalisation principle (Whitehead, 1992). In fact it was the North American brand of Normalisation, whose leading proponent was Wolf Wolfensberger, which had most impact in the UK, particularly through PASS and PASSING workshops (Lindley and Wainwright, 1992).

For Wolfensberger,

> *Normalisation implies, as much as possible, the use of culturally valued means in order to establish and/or maintain valued social roles for people* (Wolfensberger and Tullman, 1989: 281).

The theoretical basis of Normalisation, developed and refined by Wolfensberger over the years, leans on sociological theories of labelling and deviance which identify the negative images and expectations that

adhere to people with learning disabilities. These images are assumed to inform the design of services which segregate people with learning disabilities from normal roles and experiences. In these contexts, the behaviour of the devalued individual is shaped in such a way as to create a negative 'self-fulfilling prophesy'.

Within the theoretical elaboration of the Normalisation principle, of particular relevance to parents with learning disabilities was Wolfensberger's emphasis on the impact of unconscious destructive hostility towards devalued people within society as a whole and on human services in particular. The ultimate expression of this hostility, Wolfensberger has labelled 'death-making'; society's '*very well hidden policy of genocidal destruction of certain of its rejected and unwanted classes*' (Wolfensberger 1987: 141). Thus, curtailment and control of the fertility of people with learning disabilities can be seen as part of this 'death-making' impetus.

Wolfensberger argued that the means by which society creates conditions in which the lives of people with learning disabilities come to be seen as devalued and expendable is through creating negative social roles for these individuals, practically and symbolically reinforced by the structure of human services. Wolfensberger described eight of these social roles: subhuman organism, menace, unspeakable object of dread, object of pity, holy innocent, diseased organism, object of ridicule and eternal child (Wolfensberger, 1972). A number of these social roles, particularly that of diseased organism, holy innocent and eternal child, can be seen as incompatible with sexual expression, becoming a parent and childrearing. The challenge for workers in human services therefore, is to question their own unconscious expectations of people with learning disabilities, and to create opportunities for people with learning disabilities to engage in socially valued roles by teaching them the appropriate skills to sustain these roles.

O'Brien (1987; O'Brien and Tyne, 1981) translated Normalisation ideas into goals, or accomplishments, which services should subscribe to in order to support people with learning disabilities towards culturally valued outcomes[2]. These service accomplishments were very influential and found their way into the mission statements of many of the new community based services that grew up in the 1980s during the period of the development of a free market in service provision in the name of enhancing quality and choice in services (Rapley and Ridgeway, 1998). An echo of these objectives pervades the most recent government directives for learning disabilities services in Valuing People (Department of Health, 2001). However, there is a sense, in the new millennium, that Normalisation has had its day as a philosophy and blueprint for services. During the late 1980s and 1990s criticism of Normalisation raised concerns both about how the principle of Normalisation had been interpreted and applied, as well about the underlying ideas. In particular, I argue that Normalisation as a policy achieved only limited progress in enhancing the acceptability of parents with learning disabilities as far as human services are concerned, and in creating better opportunities and support for them and their children.

3.3.1 Limitations in the application of the Normalisation principle

First I consider points made by critics of Normalisation who may be broadly in agreement with its goals, but who believe that services and society as a whole have fallen short in applying its principles wholeheartedly and consistently.

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[2] O'Brien's 'five accomplishments' or goals for people with learning disabilities which services should work to achieve are:

- Community Presence – to have a physical presence in the community.
- Choice – to be given choices and decision making power.
- Respect – to be treated with respect and to make sure that the form and content of service provision reflects this.
- Competence – to be offered opportunities to enhance their skills within a community setting.
- Participation – to be supported to become active participants in community life.

The momentum behind Normalisation as a service model was a desire to liberate people with learning disabilities from abusive and dehumanising treatment in large institutions. To some extent 'Normalisation' has been synonymous with deinstitutionalisation and desegregation. In this sense the impact of Normalisation has been widespread[3].

However, critics have raised the question of whether Normalisation achieved its goal of securing valued roles and opportunities for people with learning disabilities. Interestingly, there is little that directly considers parents with learning disabilities, either in older or in more recent revisionist writings on normalisation (Brown and Smith, 1992; Williams and Nind, 1999). Therefore, in this section I examine the literature which attempts to evaluate in general terms the implementation of the normalisation principle, in terms of the goals identified by Wolfensberger and O'Brien. With regard to parents with learning disabilities we might want to consider whether they are now being offered appropriate support. Literature that reviews the discrimination and opprobrium experienced by these parents suggests that this is not the case.

Studies undertaken in the late 1980s and 1990s suggest that though physically present 'in the community' people with learning disabilities remain 'outside looking in' (Myers et al., 1998). Access to mainstream activities in employment, education and leisure are limited by continuing reliance on segregated facilities (Jahoda et al., 1990), reliance on support staff, especially for more disabled individuals (Perry and Felce, 1994), and poverty and low income (Chappell, 1994).

Studies have suggested widespread experience of social isolation (Bees, 1991) and limited opportunities to make social relationships, especially with non-disabled people (Chappell, 1994). Nor can people with learning disabilities rely on acceptance and support from their non-disabled

[3]A few large scale institutions do remain open, despite the government objectives voiced in Valuing People (Department of Health, 2001) that all people with learning disabilities transfer to housing in the community by Spring 2004.

neighbours in community settings. Although studies have identified preparedness of some non-disabled people to engage with people with learning disabilities in a variety of roles, as neighbours, employers or friends (Taylor and Bogdan, 1989; Lutfiyya, 1991), on individual level people with learning disabilities continue to meet hostility, exploitation, and even victimisation (McConkey, 1987; Flynn, 1989).

Perhaps of most concern, when evaluating the success of the implementation principle, is the persistence of limiting and discriminatory concepts among staff, especially given the reliance of many people with learning disabilities on professional support. Again, there is little research from within a normalisation perspective which explicitly looks at services' support for parenting, despite the challenge thrown down by Wolfensberger:

> *We must address ourselves to the development of supportive systems that will enable handicapped adults to lead married lives, keeping in mind that such support systems can be meaningless or even redundant unless service personnel internalize positive attitudes toward such measures* (Wolfensberger and Glenn, 1975: 30).

However, studies which examine the sort of support people with learning disabilities receive relating to their wider sexual lives suggest that there is still an unspoken expectation of services that they act as a '*container and regulator of the sexual behaviour of people with learning disabilities*' (Brown 1994: 131).

Initially, sex education literature of the 1970s and 1980s struggled with the idea of individual sexual expression being a right for people with learning disabilities. Williams and Nind (1999) identified an assumption in this literature that love, sex and fulfilment inevitably come together, underpinned by implicit judgements of what is appropriate and acceptable. Another underlying assumption was that the ideal form of intimate relationship for adults with learning disabilities was a form of 'companionate marriage' (May and Simpson, 2003) divorced from the

demands and responsibilities of bearing and raising children (Craft and Craft, 1979). Even when practitioners of a later generation have wished to adopt a more facilitative role in supporting individual choices, they find themselves positioned as taking on a more regulatory role: ruling on individuals' capacity to consent to sex; needing to acknowledge the anxieties of parents of learning disabled people; preventing and responding to 'deviant' sexual behaviour; and taking on the role of protecting people with learning disabilities from sexual exploitation, abuse and exposure to STDs (Craft, 1994).

Brown (1994: 133) went on to state:

> *The fact is that both heterosexual and homosexual options are made available conditionally to people within our society, and individuals are subject to sanctions in benefits, the lack of communal child care facilities, the availability of information and images, all of which enforce assumptions about those with whom one is supposed to have sex, live, financially support, and/or have children.*

3.3.2 Criticism of the Normalisation concept

A key criticism of the concept of Normalisation is that it unreflexively holds up societal norms and patterns of social organisation as something that people it regards as devalued should aspire to. There is an underlying assumption that '*values and norms of behaviour and appearance in society are worth striving for*' (Hattersley, 1991: 3).

Furthermore, what is 'typical' in the sense of statistically normative came to be seen as 'normal' and therefore socially valued. The original Scandinavian conceptualisation of Normalisation insisted that the requirement was for services to ensure equal treatment and equal access to ordinary patterns of life and relationships for disabled people. However, in practice, the onus shifted onto the disabled individual to adapt, to fit in, and against the odds, '*to compete in the world of the able-bodied and the able-minded*' (Walmsey 1993: 227), instead of putting the responsibility

onto social institutions to respect difference and remove barriers to the integration of disabled people (Cambridge, 1997; Ferri and Gregg 1998).

Encouraging 'devalued' people to pursue 'normal' patterns of social life may engage them in two different sets of problems. First, the 'normal' reference group, for instance the elderly (Walker and Walker, 1998) or women (Williams and Nind, 1999) may themselves suffer from discrimination, and be socially positioned as dependent or static. Indeed, orthodox Normalisation theory has come under fire from feminist theorists, who claim that it does not challenge cultural norms which are oppressive to women, or acknowledge the importance of women only space and self-help (Brown and Smith, 1992; Williams and Nind, 1999). Second, 'normal' provision itself may not be adequate or appropriate (Walker and Walker, 1998). With relation to child-rearing, 'mainstream' provision means paucity of free nursery places, deficits in affordable childcare provision, fragmented services and pressure on women reliant on state benefits to enter the job market in pursuit of low-paid jobs.

To develop this point further, 'normal' patterns of family life, in terms of the structural organisation of the 'nuclear family', which assume the autonomy of the family unit, are not going to be possible for many people with learning disabilities. If taking on parenting roles is going to be a real option for people with learning disabilities, many would need long-term support from their own families or professionals. Along these lines, Bayley (1991: 88) has pointed with concern to the stress within the Normalisation principle on

> *individualistic achievement or success-orientated societal values, which emphasise people's independence rather than their interdependence, [which] are profoundly unhelpful to people with a mental handicap (and many other people).*

Moreover, parents with learning disabilities further challenge the 'normal' ordering of family life where parents are assumed to be more able and 'intelligent' than their children. Families where children have more advanced cognitive skills than their parents, and even caring

responsibilities are felt in themselves to endanger children's wellbeing - the so called 'Huck Finn syndrome' (O'Neil, 1985; Denfeld, 1998).

A further criticism of the Normalisation principle is that it has fallen short in its examination of issues of power and autonomy between service users and service providers.

> *Normalisation offers a theory of how to improve services. As services are controlled by professionals, Normalisation has enabled professionals to retain a key role in the debate about quality. It does not challenge the legitimacy of the professional role in the lives of people with learning difficulties* (Chappell, 1992: 40).

At some level, the professional, consciousness raised through the medium of PASS/ING training, is assumed to know best. It is the professional who is the expert in 'normality', who guides the 'devalued' person into appropriate patterns of living, acting as 'a sensitive interpreter of the larger culture' (CMH, 1981: 27). Chappell (1992) has drawn attention to the functionalist basis of Normalisation, a supposition that there is a consensus between service providers and service users, and a basis of shared values, priorities and goals. She has also highlighted the way that Normalisation ignores the impact of material constraints and economic disadvantage in the social construction of 'learning disabilities'. If people were not excluded from employment opportunities and access to material advancement because of their impairments, would they be devalued or disabled in any way so as to need 'social care' support, even that designed along strict Normalisation guidelines?

3.3.3 Reflexivity – a personal journey through Normalisation

In reviewing this literature on Normalisation, and considering its impact on approaches to parents with learning disabilities, I have been led back to my own ambiguous and complex relationship towards this influential concept. I undertook my in-service training in Clinical Psychology

between 1986 and 1989, a period when Normalisation had taken root as the orthodoxy within learning disability services (especially in the North West of England where I was working). It was also a period when Normalisation was becoming operationalised within the context of the New Right's policy of 'community care' involving precepts such as 'consumer choice' and 'the internal market in health care' (Rapley and Ridgway, 1998).

My first training placement was in a large mental handicap hospital on the brink of closure. Normalisation formed the theoretical basis for our critique of the dehumanising, demeaning and at times frankly brutal practices we found in the hospital. How could any right-thinking person not advocate for the old 'bin' to be closed down? Normalisation set exciting, but exacting targets for us to work towards with our new 'clients' in the community, based on, wherever possible, an avoidance of segregated, stigmatising settings. Normalisation and the Five Accomplishments also provided us professionals, with a coherent outlook and structure and a proselytising agenda of changing the attitudes and behaviours of more lowly staff and carers, who like us were employees of the monolithic and cash-strapped NHS.

The bulk of our work in the new Community Mental Handicap Team was around community resettlement of the hospital population. At this stage I had not come across any parents with learning disabilities (maybe I imagined there were very few around), though probably would have argued that parenting was a social valued role, worthy of support. Thankfully for those of us engaged in developing new services, these arguments remained at a theoretical level, just as for people with learning disabilities themselves, many aspects of adulthood continued to have a primarily 'metaphorical' existence (May, 2000).

Since then I have noted the gradual eclipsing of the Normalisation ideal. Although, this is a point not emphasised in the published literature, my perception is that ideologically driven changes in the organisation of public

services under Thatcherism, such as the rise of general management in the NHS, the development of Social Services as the lead agency for commissioning learning disabilities services, and the proliferation of small agencies in the internal social care market have militated against the survival of a shared theoretical outlook among professionals. Mainstream services have proved resolutely unwelcoming to people with learning disabilities, and the persistence of paternalistic and protectionist attitudes inside and outside specialist services led to the propagation of the rhetoric of 'Normalisation gone mad'; the idea that Normalisation led to recklessly permissive adherence to expression of service user 'choices', even when such choices entailed risks to 'vulnerable' service users and the wider public. The outcome seems to be a renewed complacency about the segregation and exclusion of people with learning disabilities from opportunities for more fulfilling and rewarding lives. At times I can't help but miss the shared certainties and commitment to desegregation of the Normalisation era.

However, I don't think Normalisation ever had much to offer parents with learning disabilities. Many of the parents I have met over the last ten or so years would not necessarily see themselves as learning disabled, and would have had little to do with specialist services since leaving school. If they have managed to avoid labelling and to become 'integrated' within their communities, and especially if they have developed relationships with non-disabled partners, in Normalisation terms they would have already 'succeeded', even though they might be living very stressful lives, in poverty and with the threat of removal of their children ever present.

I feel that for specialist services to have taken on the role of advocating parenthood as a valued role for people with learning disabilities would have seemed a step too far. Not only because of the sort of internalised prejudice that Wolfensberger and Glenn (1975) attack, but also because of competing understandings of what parenting is about, understandings which are themselves part of the mainstream, taken for granted

assumptions about what parents should do and what children need which cannot accommodate as a starting point an intellectually impaired parent.

3.4 Parental skills and parent training

Developments in services and service ideologies brought about by Normalisation created the preconditions for 'parents with learning disabilities' to be rediscovered as a focus of professional assessment and intervention. Researchers in this field have assumed growing numbers of these parents exist in community settings and no longer feel in a position to advocate exclusion of people with learning disabilities from parenting. However, uneasiness about parenting abilities has continued in the light of studies (often from an earlier historical era) that painted a very pessimistic picture about the outcomes for children of parents with learning disabilities. With deficits in parenting taken more or less as given, researchers and practitioners developed programmes to improve parenting skills, using technologies derived from applied behavioural analysis. In this section I assess the parent training literature relating to parents with learning disabilities, and examine some of the methodological and conceptual questions raised by this work.

Despite the limitations of Normalisation as a progressive ideology for parents with learning disabilities, the structural changes brought about by deinstitutionalisation and the development of community services has brought these parents to professional attention. As young people with learning disabilities grew to adulthood 'in the community' where there are fewer mechanisms for surveillance and control (May and Simpson, 2003), they were more able to enact the same aspirations for sexual relationships and family life as their non-disabled peers. As Booth and Booth (1993: 461) have written, *'parenthood is a choice and consequence of ordinary living'.*

Nevertheless, I do not wish to suggest that the impact of Normalisation has eradicated differences in key life span experiences between people with learning disabilities and their non-disabled peers. As May and Simpson (2003) have pointed out, the assumption that the impact of the implementation of Normalisation would lead to a large expansion in the numbers of parents with learning disabilities is so far not backed up by research findings. It is likely that opportunities for parenthood are available only for the more independent and more able individuals, with more disabled individuals continuing to lead restricted lives, confined within the social straightjacket of eternal childhood. However, from the 1980s *'the fact of parenthood among people with intellectual disabilities was being increasingly recognised and accepted'* (May and Simpson, 2003: 35-36).

Statements to this effect frequently preface studies relating to teaching parenting skills to parents with learning disabilities:

> *Increased numbers of mildly and moderately retarded persons are now living independently in the community...many jurisdictions are banning involuntary sterilization...and equal rights in the areas of sexuality and family life for developmentally handicapped people are being advocated...and protected...These developments are likely to result in more mentally handicapped persons bearing and raising children* (Feldman et al., 1986: 23).

Feldman et al. (1986) suggested that not only do people with learning disabilities have more opportunities to have children, but that services recognise their right to do so, as 'normal' citizens leading ordinary lives. Therefore, parent training studies, which address the relationship between services and parents with learning disabilities often start with an assertion of the rights of such people to be parents. .

> *Allowing individuals labelled as mentally retarded to exercise their desire to participate in the life-giving process is the ultimate test of living in a free and humane society* (Greenspan and Budd, 1986: 125-6).

What then is the rationale for professional intervention in these families? Why should parents with learning disabilities not simply be left to get on with participating in 'the life-giving process'?

3.4.1 Surveying deficient parents

To answer this question, researchers have highlighted the inherent risks to children in growing up in a family with parents with learning disabilities. Parents with learning disabilities should not be left simply to get on with it, because their children will suffer. As succinctly stated by Feldman and his colleagues in a later paper: *'Children of parents with intellectual disabilities are at risk of neglect, developmental and behavioural problems'* (Feldman et al., 2002: 314).

Such assertions are drawn from the results of surveys that locate parents with learning disabilities and look at their children's developmental progress. However, in my review of the published research I found that the same survey studies were cited again and again to back up such assertions, though some are decades old, and can be contrasted with similar studies that reached the opposite conclusions. For instance, Shaw and Wright (1960) reported a widespread picture of poor quality child care in a survey from case record searches. Similarly, Reed and Reed's (1965) epidemiological study of a sample of 7,000 children from the general population found that where both parents had learning disabilities, 40% of their children had moderate or severe learning disabilities. Where only one parent had a learning disability, 15% of children were found to be similarly affected. However, wide variations on these figures have been quoted in other studies. Brandon's (1957) sample of women who had left British mental handicap institutions were in 80% of cases providing 'adequate care' for their children.

There has been less investigation into the relationship between parental intellectual level and children's emotional and social development, apart from some observations that claim that children of parents with learning disabilities are more likely to exhibit behavioural and psychiatric problems (Gillberg and Geijer-Karlsson, 1983; Seagull and Scheurer, 1986).

Other studies have argued that these children are at a greater risk of experiencing abuse or neglect, and being taken into local authority care. Though few studies make the distinction, concerns relating to purposeful abuse and injury of children seem to be rarer than concerns about children being 'neglected' (McGaw, 2000). Seagull and Sheurer (1986) found that only 11 out of 64 children remained living with their parents with learning disabilities two years after the parents had been referred to a family assessment centre. Accardo and Whitman (1990) reported that nearly half of the children in their sample were removed from home because of child abuse or neglect and Kaminer et al. (1981) in a study of 45 families reported that in 20 percent of cases, children had been removed into foster care.

3.4.2 Methodological issues

However, as other reviewers (Downdey and Skuse, 1993; Tymchuk, 1992; Tymchuk et al., 1987) have pointed out, existing studies contain substantial methodological flaws make it more difficult to evaluate the competing claims of different studies.

Tymchuk et al. (1987) made the relevant point that many of the parents who have been studied (particularly in earlier decades) have spent a significant proportion of their lives in institutions. Findings relating to this group, who are likely to have experienced a more impoverished social environment, may not be transferable to other adults who have lived all their lives in the community.

Moreover, inclusion criteria for parents with learning disabilities differ between studies. As well as previous residence in an institution (Borgman 1969; Mickelson, 1947, 1949), the various criteria have included attendance at special school (Block, 1984), being known to agencies because of previously identified problems within the family (e.g. Accardo and Whitman, 1990b; Seagull and Scheurer, 1986) or being known to the courts (Shaw and Wright, 1960). Residence in an institution or attendance at a special school are not automatic guarantees of learning disability. Nor are parents who have already been identified by agencies as having problems necessarily representative of all parents with learning disabilities. In general, samples have been of small size, and tend to be drawn from populations of low SES, where the prevalence of indices of psycho-social deprivation may operate as confounding factors.

Another methodological problem with the survey research is that researchers have not always been clear about how global assessments of 'adequate parenting' are arrived at. Whereas some have based their judgements on standards of physical care, health or physical appearance (Mickelson, 1947; Mattinson, 1970; Shaw and Wright, 1960), others emphasised the presence of affection and medical care (Floor et al., 1975).

3.4.3 Defining 'parenting skills'

Whereas earlier researchers are more likely to assume genetic factors as the mechanism of transmission of learning problems from parents with learning disabilities and their children, researchers in the 1980s and 1990s focused on the failure of these parents to provide the right sort of learning environment for their children. More specifically, parents with learning disabilities were seen to lack 'sensitivity' to their children's learning needs (Ehlers-Flint, 2002): an attribute that has been proclaimed to be '*THE influential dimension of mothering in infancy*' (Belsky 1984: 55).

Sensitivity means that the parent (here the 'mother' is assumed to be the key caregiver) is aware of her child's behaviour, she is able to interpret that behaviour with reasonable accuracy, and supply prompt and appropriate responses. In the last two decades psychologists have emphasised the early emergence of perceptual, social and communication skills (for example, Donaldson, 1984; Brazelton and Cramer, 1990). Therefore, the parent needs to be actively engaged in stimulating and facilitating the child's development in line with these reconceptualisations of early infant skills.

3.4.4 Parent-child Interactions

This is an area where researchers have found parents with learning disabilities lacking, with negative consequences for their children in terms of an elevated risk of developmental delay and low academic performance (Greenspan and Budd, 1986; Whitman et al., 1989; Accardo and Whitman, 1990; McGaw, 1994; Feldman and Walton-Allen, 1998). Instead of using survey material, these researchers tended to employ observations of parents and children, usually in clinic settings. Thus, Mira (1982) and (1984) focusing on parent-child interactions, concluded that mothers with low IQs engaged in less varied and supporting and more punitive and restrictive interactions with their children compared to middleclass mothers. Feldman et al. (1985) and (1986) also noted that mothers with learning disabilities were less affectionate, responsive, accommodating and contingently reinforcing to their children, compared to both middle and low economic status mothers.

However, in a similar study, Tymchuk and Andron (1992) observed that although learning disabled mothers showed less of some of the approved interactional behaviours, especially praising and labelling, in general,

> *these mothers [with learning disabilities] did not differ substantially from other mothers of the same cultural and economic backgrounds* (Tymchuk and Andron, 1992: 29).

Interestingly, neither Feldman and colleagues or Tymchuk and Andron (1992) found that a supposedly suboptimal style of interaction displayed by mothers with learning disabilities had any substantial negative effects on children's development[4].

3.4.5 Teaching parenting skills

An underlying orientation of the studies discussed above is to view parenting as a job (Young et al., 1997) with a set of measurable, observable, teachable skills. Skills training techniques for people with a range of identified behavioural 'deficits' or 'excesses' were developed in the 1960s and 1970s, using operant behavioural techniques such as task analysis and forward and backward chaining. Parent training and support packages as effective means to change children's behaviour followed on from this (Forehand and McMahon, 1981; Dangel and Polster, 1984).

Parent training programmes have multiplied in recent years (Fine, 1989; Pugh et al., 1994; Wolfendale, and Einzig, 1999) in a social climate where parents are seen as having a crucial impact on children's development, with a corresponding dearth of confidence in schools' ability to change children, where families are considered to be under increasing societal stress, and where 'child development experts' lay claim to authoritative new scientific knowledge on childrearing (Fine and Henry, 1989). However, such programmes have not been designed to reach out to and include parents with learning disabilities. Therefore, I concentrate on

[4] In their study of 37 pre-school aged children born to mothers with learning disabilities, McConnell et al. (2003) found that after controlling for possible organic pathology, there was no significant deviance from age-norm expectations for these children in key developmental domains. Nor was there any correlation between the children's developmental status and characteristics of the mother or the home environment. Such studies raise interesting questions about children's resilience, and the importance of other factors apart from mother-child interactions in promoting child development.

reviewing parent training programmes specifically orientated to these parents, though I return to wider debates about parent training later.

There is considerable variation in the choice of skills targeted within parent training programmes. Targeted training goals have included improving household organisation and childcare skills, (Whitman et al., 1984), identification and response to high risk home situations (Feldman, 1986; Tymchuk et al., 1988; Llewellyn et al., 2002), cognitive skills in decision-making (Tymchuk et al., 1988) and parents' response to children during play (Peterson et al., 1983; Feldman et al., 1986; Feldman et al., 1989; Tymchuk and Andron, 1992).

On the whole, the picture from these studies has been optimistic, in that many of the targeted parents do manage to acquire new skills in a variety of areas. However, authors have acknowledged problems in generalisation (Feldman et al., 1986; Bakken et al., 1993), highlighted in Budd and Greenspan's (1985) survey of 16 behaviourally orientated programmes. Professionals involved in running the programmes reported that moderate or extensive positive improvement in the referral problem was evident in 43% of 52 families, and only 18% of families demonstrated moderated or extensive generalisation. Tymchuk and Andron (1992) concluded that parents who have additional problems such as mental health or medical problems may need special support in order for them to undertake the changes in behaviour targeted by parent training programmes.

3.4.6 Critical review of studies

Despite the generally positive conclusions of these studies, the results should be viewed with some caution. Again, there are methodological problems. In general, the research literature on parent training concerns parents who are not coping, who have had children removed in the past, or who are in contact with child protection services (Fantuzzo et al., 1986;

Bakken et al., 1993) or whose children have been referred to services because of identified problems. Such studies typically involve very small sample sizes, unsatisfactory control groups, brief periods of observation, and non-naturalistic settings for observation. In addition, researchers tend to focus only on mothers with learning disabilities (Painz, 1993); moreover, these tend to be mothers with very young children (Tymchuk and Andron 1992), as opposed to school aged and teenaged children.

There are also wider conceptual issues which I argue means that 'parent training' cannot be seen as the answer to the 'problem' of parents with learning disabilities.

> *As a number of commentators have pointed out, researchers into the parenting skills of parents with learning disabilities have neglected to adopt a systematic definition of "parenting", nor have they laid down minimum standard of good enough parenting against which parents with learning disabilities can be measured* (Woodhouse, 1997: 146).

Given this state of affairs, how can proponents of parent training for parents with learning disabilities be sure that they are focusing on key components of parenting? How are they to decide whether a parent with learning disabilities has or has not reached a basic, reasonable standard of child care without the professional trainer falling back on their own cultural and class biases (Booth and Booth, 1996; Tymchuk, 1992)?

> *Our experiences suggest that mental health professionals in clinical practice commonly invoke 'middle-class' expectations and/or adult adaptive functioning as yardsticks in evaluating clients for parenting fitness* (Budd and Holdsworth 1996: 3).

Often the assumption seems to be that having learning disabilities is in itself grounds for intervention. Areas where parents with learning disabilities may be functioning well as parents are overlooked. Ehlers-Flint (2002) suggested that mothers with learning disabilities seemed able and willing to express the emotional aspects of nurturing such as holding, cuddling, and unstructured play. Tymchuk and Adron (1992) found that parents with learning disabilities expressed more affection and comforting

towards their children than non-disabled controls – a finding not commented on in their published paper.

Another question is whether structured 'training' sessions addressing specific skills identified by trainers are the best way to support parents to learn and develop. Llewellyn (1997) suggested that like other parents, most parents with learning disabilities pick up ideas, tips, skills and strategies through a variety of informal sources, and then develop and refine their parenting practice in real life situations. Though they may have difficulties in accessing some informal sources of information, including antenatal services and written health education, in common with many other parents, parents with learning disabilities refer to everyday parenting experiences and 'family traditions', as shaping parenting practices. *'Learning to parent is an ongoing process, worked and reworked to meet the changing and stable demands of everyday family life* (Llewellyn, 1997: 58).

It may be important to note that, unlike other studies, parents in Llewellyn's sample had not been identified by child protection services because of concerns about their children. Perhaps parents with learning disabilities who are assessed as not coping have had less exposure to positive parenting role models. Ehlers-Flint (2002) speculated that many of these parents are socialised differently because they are not expected to be parents. Moreover, several have had negative experiences themselves as children, with a number experiencing neglect and abuse (Tymchuk, 1993; McGaw, 1994; Ehlers-Flint, 2002).

In a later paper, Llewellyn and colleagues also made the point that parents' care of children has to be understood in a real social context, which might not be supportive of the sorts of training goals prioritised by professionals. Llewellyn et al. (2002) conducted a home teaching programme that addressed the management of home dangers, accidents and child illnesses. They found that not only '*parents participating in the HLP [Home Learning Programme] often had more immediate concerns*

and worries than engaging in a home-based lesson' (Llewellyn et al., 2002: 348), but also such parents may not be in control of the environment in which they live with their child in order to make it safer. This observation links with Tymchuk's (1991) point that poor people in general, regardless of learning disability, seem to be at great risk for home accidents.

Such research brings to the fore issues for parents with learning disabilities, such as poverty, powerlessness, and childhood experiences of abuse, which are likely to impact on the environments they provide for their own children, but which are unlikely to be addressed by behavioural parenting skills programmes.

Consequently, researchers are increasing aware of the influence of wider social factors on parenting, particularly the impact of lack of social support (Llewellyn 1995, McGaw, 1997; McGaw et al., 2002; Stenfert Kroese et al., 2002), taking note of ecological models of child development and parenting (Wahler, 1980; Bronfenbrenner, 1992). For example, Feldman and Walton-Alllen (1997) pointed out that lack of social support was related to more behaviour problems in children, and Feldman et al. (2002) asserted that more 'social support satisfaction' related to more 'positive maternal interactional style'. Recent interventions therefore have identified that a key goal for parents with learning disabilities is to develop social skills and expand their social networks. McGaw et al. (2002) used a cognitive-behavioural approach to teach skills to *'aid the parent in maintaining adequate support through personal relationships'* (McGaw et al., 2002: 356).

3.4.7 The wider context: Rose's (1999) analysis of the rise of the 'psy-complex'

This research on parent education for parents with learning disabilities seems somewhat divorced from 'mainstream' debates on parent education in contemporary Britain. On the one hand, 'feckless parents' are vilified and legally coerced into parenting courses when their children get into trouble. On the other hand other parents, ever more self-conscious and self-reflective about their role as parents and their responsibilities to promote their children's development, flock to parenting classes (Moorhead, 2001). In this section I examine how parent training relates to contemporary political and social trends and consider the implications for parents with learning disabilities.

In language which recalls Conservative Secretary of State for Social Services Keith Joseph's identification of a 'cycle of deprivation' as the reason for persistence of delinquent and ungovernable members of society despite advances in poverty reduction and social care (Smith 1997; Rose, 1999), the current New Labour administration targets irresponsible parents as the main barrier to social harmony in neighbourhoods and schools. Indeed, there is growing intolerance of what is perceived as parents' inability to control children, as politicians focus tough talking 'law and order' rhetoric on children's 'anti-social behaviour'. Parent blaming is evident in parenting orders introduced in 2000 to compel parents whose children get into trouble with the law to attend parenting courses. More recently the then Education Minister, Estelle Morris has proposed extending parenting orders to parents of children who 'cause mayhem in the classroom'.

> *Yob parents are to blame for a growing crisis of child and teenage delinquency sweeping Britain, undermining education and leading to street violence, the Government will claim this week.*
>
> *In a deliberate and controversial move to focus the raging debate on school indiscipline on parents rather than children and teachers,*

> *Estelle Morris, the Education Secretary, will say that 'feckless' parents are undermining the good work of schools*[5] *(Ahmed and Bright, 2002).*

These inadequate parents are increasingly demonised as other parents become more self-conscious about their competencies in rearing children. Rose (1999), employing a Foucauldian 'archaeology of the present' has suggested that the rise of the '**psy-complex**' involving child development experts, self-help literature, health, education and social service initiatives have smoothed the way for the internalisation of norms and goals of child care into the soul of the modern parent. In this process of subjectification, the image of the child as a developing being dependent on its parents to maximise its emotional and cognitive potential through incorporation of 'sensitive' and responsive pedagogic practices into the fabric of everyday family life (Pitt, 2002; Walkerdine and Lucey, 2002) becomes incorporated into the parent's own private fantasies and desires. The requirements of the state that parents educate, socialise and discipline their children are thus exerted through the enactment of the parent's own deeply and personally held beliefs and wishes. Parenting classes (usually accessed voluntarily, sometimes privately run and expensive according to Moorhead, 2002) become a public forum for the self-regulation of these private desires.

'Being a good parent' therefore is seen as a private responsibility, though one which requires constant fine tuning, self-criticism, and support from experts and parent educators. Parents who have failed to internalise these precepts are positioned, Rose argues, far beyond the pale and are

[5] Brought to power in 1997 on an election slogan of 'Education, Education, Education' and a pledge to raise educational standards in order that the UK can compete in the increasingly globalised and technological employment market, New Labour are now being evaluated in terms of their success in meeting their educational goals. Although the evidence suggests that more school pupils are reaching preset targets in basic educational skills, there still seems to be a hard core of underachieving pupils, many of whom come to school with pre-existing difficulties such as lack of English language skills, disabilities, refugee status, and home backgrounds marked by poverty. In this context blaming parents for schools' limitations in being able to address these complex problems may be seen as deflecting possible criticisms of New Labour's real ability to meet their own educational targets.

therefore liable levels of state interference and coercion which would normally be seen as inappropriate state intrusion into private family affairs.

Given the dearth of specialist services for parents with learning disabilities, it is unlikely that many of these parents will be able to access the sort of parent training reviewed in earlier sections. If their children are disruptive at school or get into trouble with the law, in common with other 'failing' parents, they are more likely to be at the receiving end of punitive and legally sanctioned government initiatives preoccupied with raising education standards and eradicating 'anti-social behaviour'. In the hard-hitting rhetoric that has accompanied the introduction of these programmes, including compulsory parenting courses, there is little consideration of the individual difficulties these 'feckless parents' may be living with such as learning disabilities or mental health problems, nor structural difficulties such as unemployment, poverty, and discrimination.

It is the impact specifically of discrimination on the lives and experiences of disabled parents that is the focus of the social model of disability which I examine in the final part of this literature review.

3.5 The social model of disability, and beyond

In this section I examine the **social model of disability** and examine the possibilities it offers parents with learning disabilities, as a theoretical approach which constitutes 'disability' as a result of social processes; as the inspiration for a body of research which exposes discrimination and oppression; and as a focus for intervention and social change. My account cannot ignore the limitations of the social model for this group of disabled people, and in a reflexive piece at the end I describe some of the contradictions I have encountered in grappling with the social model position in my professional life.

The social model of disability asserts that there is a distinction between 'impairment' and 'disability'. The starting point for the formulation for this model of understanding disability is often seen to be the reconceptualisation of disability promoted by the Union of the Physically Impaired Against Segregation (UPIAS) in the mid 1970s.

> *Impairment – lacking part of or all of a limb, or having a defective limb organism or mechanism of the body.*
>
> *Disability – the disadvantage or restriction of activity caused by a contemporary social organisation which takes no account of people who have physical impairments and thus excludes them from mainstream social activities* (UPIAS, 1976, quoted in Oliver, 1990: 11).

The distinction between impairment and disability has been cited as the 'one big idea' of the social model of disability. It is a social model because disability is viewed as socially created, in contrast to individualised models of disability which conceptualise disability and restriction as arising naturally and inevitably from some underlying lack or damage (Barnes 1990). This individualised approach is typified by the definition of disability enshrined in the 1995 Disability Discrimination Act:

> *Either a physical or mental impairment which has a substantial and long-term adverse effect on a person's ability to carry out normal day-to-day activities* (Department of Health, 1995).

Thus the person's disability is the observable manifestation of the underlying impairment. The greater the impairment the further the person's behaviour and abilities will deviate from the normal and the more help and intervention the disabled person will need from professional services.

Disability is seen therefore as a problem residing within the individual, resulting from their particular deficiencies. Moreover, the disabled person is regarded as a victim of a personal tragedy (Oliver, 1990), deserving pity and aid from 'normal' people. These sorts of images of disabled people as

victims of misfortune (who might possibly be able to overcome their plight through heroic efforts or through the intercession of selfless helpers) dominate media reports of disabled people, (Barnes 1992) and are used by charities to raise money to fund their work with disabled people.

This individualised, personal tragedy approach to disability is often described as a 'medical model' of disability (Oliver, 1990). This label relates to the emphasis on individual pathology as the cause of disability, and the dominance of doctors in organising and controlling services for disabled people. According to this analysis, the medical model has also given rise to an army of disability professionals, who are orientated towards the 'treatment', and 'rehabilitation' of individual disabled people, in line with their 'expert' knowledge and technologies, which paradoxically further disempower and silence disabled people.

In contrast to the 'medical model' the social model of disability suggests that it is the 'disabling barriers' in our society that create the problem of disability, not the nature of the individual's impairments. This model encourages social action and activism (Campbell and Oliver 1996), because it encourages people with and without disabilities to imagine and collectively demand alternative social structures which support people with impairments in 'enabling environments.' The input of professionals is seen as problematic, and with a reversal of 'medical model' understandings of the relationship between the 'expert' and the disabled 'client', Oliver has drawn attention to the dependency of disability professionals on disabled people for their salaries, professional standing and quality of life (Oliver, 1990; 91).

3.5.1 Research informed by the social model and parents with learning disabilities

The development of the social model of disability has had a very significant, and in some cases, transforming impact on disability studies, the organisation and activism of disabled people, and on the organisation of services for disabled people (Campbell and Oliver, 1996)[6]. However, the evidence for the effect of this model on the lives of people with learning disabilities and research involving this group of people is more difficult to find. Nor is there a great deal of British research relating to people with learning disabilities which takes as its starting point the principles of the social model, namely that disability is socially created and therefore barriers to full participation whether legal, attitudinal, cultural or material must be identified and attacked. Social model rhetoric at least is beginning to make its mark on policy documents relating to people with learning disabilities. The Prime Minister's foreword to Valuing People (Department of Health, 2001: 1) acknowledged that *'almost all [people with learning disabilities] encounter prejudice, bullying, insensitive treatment and discrimination in some point in their lives.'*

Nevertheless, the theme of the Valuing People as a whole relates to improving services for people with learning disabilities, rather than a reconceptualisation of what 'having a learning disability' means and social transformation through legislation aimed at creating a more equitable and tolerant society.

From a more explicit social model perspective, Coles (2001) used illustrative case studies to suggest that evidence of social model thinking, emphasising choice, autonomy and acceptance of disabled people can be found in relationships between paid workers and people with learning disabilities. He concluded that the social model can make its mark on

[6] Though of course, this is not to deny that a great deal more needs to be achieved.

services for people with learning disabilities, and should be a key component of training for all service providers.

Goodley (2000, 2001) also emphasised the progress made by self-advocacy groups of people with learning disabilities, as the embodiment of the social organisation of people with learning disabilities and their resistance to oppressive practices. Goodley's research into self-advocacy was centred on the biographies of key British self-advocates. He asserts the importance of letting people with learning disabilities tell their own stories:

> *Narrators often present stories in ways that accent resilience over adversity... consequently, narrators may recount past experiences in ways that emphasize their activity, intention and direction* (Goodley, 2001: 218).

Booth and Booth also used a narrative methodology to examine the experiences of parents with learning disabilities in their ground-breaking study (Booth and Booth 1994). They found that this approach not only gave disabled people a chance to advance their own versions of reality, but it also revealed the social pressures and structures that shaped people's lives. The accounts illustrated competency, resilience and resistance on the part of their informants, while also documenting evidence of 'system abuse'; the process by which inflexible, inaccessible and prejudiced service system disable and disadvantage parents with learning disabilities.

Other research relevant to a social model analysis of the experience of parents with learning disabilities has further documented how these parents have been discriminated against within the child protection and legal system (Levesque, 1996; Booth, 2000). An initial 'social barrier' that they have to overcome is the fact that simply having the label of learning disability will expose them to the assumptions that they are inadequate parents and that their difficulties are irremediable (Hertz, 1979; Hayman, 1990; Marafino, 1990; Field and Sanchez, 1999; McConnell and Llewellyn, 2000; McConnell and Llewellyn, 2002). Courts have been

shown to be prepared to accept lower standards of proof of incapacity as parents in deciding to terminate parental rights of parents with learning disabilities. Studies of how these parents fare in child protection cases (Hertz, 1979; Hayman, 1990; Marafino, 1990; Field and Sanchez, 1999) have cited examples where the mere identification of mental disability has been enough to justify the removal of children.

McConnell and Llewellyn (2002), for example, quoted several studies that suggest that parents with learning disabilities are more likely to have their children removed than any other group of parents who appear before the courts on child protection matters, suggesting that '*mental retardation may result in an application of higher standards of parenting than are applied to other parents*' (Field and Sanchez, 1999: 272).

McConnell and Llewellyn (2000, 2002) further pointed to three factors which militate against parents with learning disabilities receiving fair treatment. First, a vague definition of what constitutes child maltreatment can give rise to prejudicial judgements based on negative stereotypes of these parents. Second, experts who provide testimony in these cases are likely to use a 'deficit model' in their reports, emphasising IQ scores and lack of skills (this point is also made by Green and Vetere, 2001, who further criticise 'flying experts' for ignoring the practical social and economic context that may make parenting a struggle for parent with learning disabilities). Third, these parents often receive inadequate legal representation that leaves them at a disadvantage when confronting the very complex legal system (Hayman, 1990; Swain and Cameron, 2003) as well as other processes within the child protection system such as child protection conferences, reviews and planning meetings. These meetings are attended by large numbers of professionals, are very long and often rely on written materials that are not comprehensible to parents with learning disabilities (Green and Vetere, 2001).

Goodinge (2000) found further barriers confronting disabled parents included lack of accessible information about services (also Wates, 2003),

and restrictive eligibility criteria that hindered access to services, *'because adult services did not recognise the potential impact of being a parent and for children's services parental disability was not an important factor'* (Goodinge 2000:5).

Moreover accessing care at home was particularly difficult for disabled parents because of demarcation issues between teams, particularly about budgets (Goodinge, 2000; Wates, 2002, 2003).

In line with a social model critique of professional involvement, Booth and Booth (1996) stressed how professional intervention in the lives of parents with learning disabilities can be 'competence inhibiting'. They gave many examples of how professional input can be dependency-creating (Oliver 1990), undermining parents' authority and autonomy and denying them opportunities to learn and practise skills. Moreover, Llewellyn's (1995) ethnographic study of parents with learning disabilities in Australia concluded that from the perspective of the parents, professionals ignored any difficulties in understanding and learning new concepts, or gave conflicting advice. Studies have suggested that parents with learning disabilities are often exposed to an overwhelming number of professionals (Andron and Tychuk, 1987; Llewellyn 1995; Espe-Sherwindt and Crable, 1993; Goodinge, 2000) with often poor quality of joint work between different services (Goodinge, 2000) as well as lack of systematic procedures for sharing information and conducting joint work (Wates 2002). Goodinge (2000) found widespread evidence of a 'Professional Knows Best culture' where disabled parents are unlikely to be consulted about planning or organisation of services, even when staff working with disabled parents were found to have limited skills and knowledge around disability. It can be argued, therefore that it is these structural limitations that undermine and disable parents with learning disabilities, leaving alone difficulties or deficits on the individual level.

3.5.2 The exclusion of people with learning disabilities

The studies described above suggest that there is some research which makes links between the social model of disability, with its emphasis on exposing disabling barriers to inclusion and participation, and the experiences of people with learning disabilities, and parents with learning disabilities in particular. However, a number of writers have expressed disappointment at the very limited impact that the social model has had on the lives of people with learning disabilities and on research relating to their experiences (Chappell, 1998; Chappell et al., 2001; Goodley, 2001; Walmsley, 2001; McClimens, 2003). Work by writers concerned with learning disability is conspicuous by its absence within the disability literature. As a result, theorising about learning disability from a social model perspective has been underdeveloped.

Chappell (1998) argued that social model writing concerns itself primarily with physical and sensory impairments; in this context 'able-bodied' is seen as the opposite of 'disabled'. She contended that the 'focus on the body' in social model writing has led to a concentration of critiquing the cultural myth of 'bodily perfection' and its role in oppressing disabled people and discounting their sexuality. However, she questioned the relevance of such debates for people with learning disabilities, who have been portrayed as dangerously and promiscuously sexual.

There is also evidence that the experiences of people with learning disabilities have been marginalised in the wider disability movement, and that they have not always been invited to take a central place in the organisation and activism of disabled people:

> *People with learning difficulties face discrimination in the disability movement. People without learning difficulties use the medical model when dealing with us. We are always asked to talk about advocacy and our impairments as though our barriers aren't disabling in the same way as disabled people without learning difficulties. We want concentration on our access needs in the*

> *mainstream disability movement* (Aspis, quoted in Campbell and Oliver, 1996: 97).

With remarkable honesty, Tregaskis (2004), a disabled researcher and activist, reflected on her own oppressive actions towards a man with learning disabilities whom she encountered on her research site.

Both Aspis and Tregaskis have drawn attention to complex relationships of power and authority within the disability movement, and the 'hierarchy of impairments' (Deal, 2003). Aspis has developed her argument by stating that full inclusion within the disability movement for people with learning disabilities has been hampered by other disabled people assuming that people with learning disabilities are incapable, 'stupid', limited and unsophisticated in their thinking, as well as very negatively viewed by non-disabled people, and therefore a liability to the disability movement.

3.5.3 The issue of impairment as a biological given

> *There is need to work and for an understanding of 'learning difficulties' as a fundamentally social, cultural, political, historical, discursive and relational phenomena, rather than sensitively recognising the existence of an individual's 'naturalised impairment* (Goodley, 2001: 210).

From a consideration of the social position of people with learning disabilities within disability writing and organisation, I now turn to an exploration of the position of 'learning disability' within the epistemological assumptions of the social model of disability. Whereas many disability writers have interrogated the causes and processes of disablement that society imposes through exclusionary practices, for some the issue of **impairment** has remained inadequately theorised (Hughes and Patterson, 1997; Goodley, 2001; Tremain, 2002). The UPIAS definition quoted above suggests that *disability* is the lived experience of exclusion brought about by socially constructed, localised and historically bounded processes, ideologies and institutions, and *impairment* is the 'objective',

biological lack, dysfunction or injury that makes the individual vulnerable to discrimination and exclusion. Disability is therefore about society and culture, whereas impairment is about the body and its nature. Hughes and Patterson (1997) and Tremain (2002) have challenged this formulation of impairment as constituting an implicit restoration of the medical model, since talking about impairment in this way surrenders the body to the same dominant biomedical discourses and practices that the social model set out to defy.

> *The distinction between disability and impairment demedicalises disability, but simultaneously leaves the impaired body in the exclusive jurisdiction of medical hermeneutics* (Hughes and Patterson, 1997: 330).

Within the social model, people with learning disabilities are placed in a position where their assumed underlying organic 'impairments' assume the status of biological fact. What is more, Goodley has suggested that this assumption further marginalises people with learning disabilities within the disability movement, as they become associated with their presumed unchangeable, static and socially inert 'organic impairments' and marked *'the biological we cannot sociologise'* (Goodley, 2001: 211).

3.5.4 Post-modernism, Foucault and the body

By contrast, the 'turn to impairment' rejects the concept of the 'naturalised' and essentialised impaired body and the Cartesian dualism inherent in the separation of disability/social and impairment/natural. As has been pointed out (Hughes and Patterson, 1997; Goodley and Rapley, 2001; Tremain, 2002) there are analogies here with Judith Bulter's post-modernist critique of the split between 'gender' as social practices, and 'sex' as biological substrate in orthodox feminism, which queries the possibility of embodiment which exists outside social practices and discourse.

> *To claim that discourse is formative is not to claim that it originates, causes or exhaustively composes that which it concedes; rather, it is to claim that there is no reference to a pure body which is not at the same time a further creation of that body.* (Bulter, 1993: 10.)

Taking up a post-modernist position, Goodley and Rapley (2001) and Tremain (2002) have drawn on the ideas of Foucault (1970, 1975, 1983) to understand how the body and its impairments have come to be the subject and object of knowledge. Foucault argued that the body is known and understood through the 'regimes of truth' created through the normalising practices of the psy-complex (Rose, 1999), the institutions of medicine, psychology and social work which emerged in concert with the rise of capitalism. The procedures and operations, or 'technologies' of these institutions divide and categorise the normal and abnormal. In the case of learning disabilities these technologies include not only IQ tests and assessments of maladaptive functioning (Goodley, 2001), but also the rituals and practices inscribed not only in learning disability services, (McIntosh, 2002) but also in everyday language and practices which reference conceptions of (in)competence and difference (Peter, 2000).

3.5.5 Challenging epistemologies: research in learning disabilities

The research opportunities opened up by these theoretical approaches are only just beginning to be explored in learning disability studies. Once the basis of naturalised intellectual impairment has been challenged, it loses its power to define 'what is wrong' with the individual. Instances where behaviour is understood as manifestations of underlying impairment can be seen as examples of the operation of power/knowledge and not a final 'objective' account which determines all that can be spoken of meaningfully in relation to the individual, creating the possibility for an appreciation of the individual's competency and efficacy to emerge.

In this light, Rapley (2004) has used discourse analysis to examine how 'learning disability' is produced and resisted in interviews between users of

learning disability services and non-disabled conversation partners. Rapley has suggested that '*what is to count as (in) competence is negotiated and constructed locally, and for local purposes, by local means*' (Rapley, 2004: 202 (emphasis in original).

In their interviews, staff reproduced themselves as providers of care and their clients as incompetent and in need of care, even when the responses of people with learning disabilities, according to Rapley's ethnomethodological analysis, yielded up many examples of skilful language use and fine-tuned sensitivity to discrimination and negative moral evaluations.

The people with learning disabilities in Rapley's study were portrayed as producing and negotiating a variety of identities to bring off interactional goals, in the same way that these sorts of achievements can be found in the conversations of non-disabled speakers. This scepticism about the acceptance of intellectual impairment and incompetence as a defining characteristic of people with learning disabilities is shared by other writers who have looked specifically at the lives of parents with learning disabilities. Taylor (2000) noted that Bill and Winnie, the parents labelled 'mentally retarded' that he studied, along with their kin and friends, defined themselves and others in terms of personal characteristics and social relationships, not disability labels. He therefore concluded:

> *The definition of a person is to be found in the relationship between the definer and the defined, and is not determined by the abstract meanings attached to a group of which the person is a part* (Taylor, 2000: 84).

Booth and Booth (1994) also emphasised the resilience and skill of the parents with learning disabilities in their study. Furthermore, they challenged the idea that 'competence' (for instance with relation to parenting) is an integral attribute of the individual subject, and a reflection of 'underlying impairment'. They suggested that parenting outcomes can be seen as the production of 'distributed competence' which is more a reflection of the resources in the parents' networks.

> *The notion of what might be termed 'distributed competence' attests to the fact that parenting is mostly a shared activity and acknowledges the inderdependencies that comprise the parenting task* (Booth and Booth 1994: 2001).

This understanding of the subject accords with a post-structuralist critique of the primacy of individual experience. The Booths challenge the premise of the isolated subject who is either capable or incapable of autonomy and rationality. Instead, the idea of 'distributed competence' calls attention to the shared social creation of knowledge and experience, and conceptualises a subject that is a 'community of selves' (Goodley and Rapley, 2001).

The sorts of interventions that reflect the principles represented in Booths' work focus on self-advocacy, self-expression and mutual help for parents with learning disabilities (Women as Parents Group, 1993; Booth 1996; Booth and Booth 2003a, 2003b). Although the experiences of pain and loss experienced by many parents with learning disabilities are acknowledged, these interventions aim to build on the parents' capabilities and the opportunities for mutual support and joint action. Research on the effectiveness of these sorts of interventions is so far very patchy. There is little to counter the concern that learning disabled parents are likely to occupy a marginalised place in organisations of disabled parents, as people with learning disabilities do in wider organisations of disabled people.

3.5.6 Reflexivity: social model ideas in real-life settings

Coming across the theoretical work on the social model of disability described above a number of years ago made a major impact on my thinking as a learning disability professional. I found myself rewriting psychological reports on my clients in order to illustrate examples of exclusion and discrimination, avoiding medicalised and individualised lists of deficits and disorders. Further reading associated with this dissertation

on the social construction of 'impairment' led me to a more fundamental questioning of the legitimacy of the very structure and function of specialist learning disabilities services. Who on earth were our 'client group' anyway? By treating them as if they had an essential characteristic in common, one that we defined as 'learning disabilities' were we not contributing to the perpetuation of the myth that such a category reflected some underlying reality, and that categorising people according to some notion of natural 'intelligence' was a good idea? Should we not be devoting our energies to breaking down barriers in mainstream services, so that all citizens can have equal access to community resources?

On the other hand...I am employed as a clinical psychologist by a multi-disciplinary Community Learning Disability Team; an organisation which is largely structured around a medical, deficit model of learning disabilities (although we recognise the limitations of a strictly medical model approach enough to subscribe publicly to a 'bio-psycho-social model', which encourages consideration of social 'factors' to be included in our formulations). Moreover, I am expected as a clinical psychologist to fulfil a gate-keeping role to the specialist service, and on occasion to administer psychological tests to discover whether a referred individual is 'impaired enough' to merit receiving support from members of the Community Learning Disability Team. And accessing our team can offer a number of opportunities for people with learning disabilities and their families and carers, not least contact with a dedicated and hard-working group of professionals who have a thorough and empathic understanding of the life experiences and discrimination faced by people with learning disabilities and their families[7]*. Most of us try our best to build links with community organisations and support our clients to access them, often in the face of indifference from the mainstream organisations themselves.*

I am particularly aware of these contradictions for parents with learning disabilities. Classifying parents referred to our service as 'parents with

[7] Thanks to Suzanne Wilson, a psychology colleague in the Tower Hamlets Community Learning Disability Team for many stimulating conversations on this topic.

learning disabilities' subjects them to negative assumptions, as well as heightened surveillance and control (May and Simpson, 2003), particularly from child protection agencies. However, there is also an opportunity to document a fuller picture of the difficulties and challenges these parents may be facing (often not directly related to 'learning disabilities') and for them to access some additional support. It is debatable if it is to the parents' advantage whether perceived parenting deficits become ascribed to an 'underlying impairment' or to other negative personal characteristics (laziness, lack of motivation, unco-operativeness). 'Being disabled' might absolve the parent from some blame, but may also been seen as a factor unamenable to change.

These are some of the dilemmas that I face trying to enact some of the theoretical positions described in this section. I have also encountered some further difficulties with the social model in real-life settings. First, the rhetoric of the social model, with its reference to discrimination and rights (such as the 'right to be a parent' or the 'right to family life') can polarise professionals from disability and children and families teams, as they argue about whose 'rights' takes precedence, that of the parents or the children. Given the accepted orthodoxy that constructs children's 'rights' and 'needs' as paramount (Anglin, 2002) parents' perspectives will inevitably lose out in this sort of debate.

Second, the social model of disability, which proposes itself in opposition to the medical model that emerged historically with the rise of Western capitalism, tends to disregard the possibility that there are many other 'models' of disability that have developed in different cultural contexts. Many of the people that I work with in the East End of London are from the Bangladeshi community and it is clear that they and their families have access to a wider range of disability theories, often those which foreground spiritual or family factors. Among this community it is very usual to find even people who access a lot of day to day support from carers getting married and having children (Hepper, 1999; O'Hara and Martin, 2002). What constitutes 'competency', 'adulthood' and 'children's

needs' are clearly different in different cultural contexts. My experience of trying to understand and connect with these different 'models of disability' as well as my reading of the work of Mark Rapley and the Booths, has highlighted for me the usefulness of seeing learning disabilities as not so much a fixed identity, but more of a locally negotiated and culturally constructed category, which relates to other values, concepts and materially derived opportunities and constraints in the specific cultural setting.

Chapter Four: Discourse Analysis as Theory and Methodology

4.1 Introduction to Chapter Four

In this chapter I tackle issues relating to theory and methodology, in such a way that the two domains of investigation are intertwined in a way not usually found in traditional psychology or social psychology reports. I take this course of action because discourse analysis as an approach to interrogating research data raises important ontological and epistemological issues (not all of which I will be able to expound in this dissertation, even if I had the academic credentials and confidence to do so). As Hollway (1989: 1) has asserted: *'I have come to believe that the way psychology keeps theory and method separate is a serious contributory factor to its problems',* where we could speculate that the problems that she refers to include uncritical and unreflexive claims to scientific 'objectivity', built in biases relating to class and gender, and a tendency to present speculative psychological constructs in a reified form as uncontested 'facts' about universal human experience.

Therefore, I am advocating a way of doing social science, from a social constructionist perspective, which sees all forms of knowledge as shaped by culturally and historically determined preoccupations. These preoccupations create the objects of social scientific study, and the role of language in this

'act of creation' is key. In this research, my central question is how the 'parent with learning disabilities' is talked into existence by professionals who have to negotiate the preoccupations of their culture and era. No less than the social scientists whose writings I have reviewed in the previous chapter, my research participants are involved in the social construction of the 'parent with learning disabilities'. In the following section I outline some of the key concerns of the social constructionist approach and how it foregrounds the use of language in creating social phenomena

4.2 Social constructionism and discourse analysis

> *At times I felt very annoyed with myself that I could not fit the mould of my original training. At other times, I felt angry with the routine way that social psychology was practised* (Cherry, 1995: x).

In her 1995 book, Frances Cherry drew attention to the 'Stubborn Particulars' of social psychology, the specific details which root social psychology research within the context of particular historical and cultural trends. She challenged the message of 'routine' social psychology; that its task is to uncover essential truths about human behaviour using scientific, value-free methods. Cherry (and other social psychologists who locate their work as following on from the 1970's 'crisis' in social psychology) suggested that this message and its application in research investigating the impact of 'the social' on 'the individual' in itself is historically circumscribed and shaped by the requirements of the state to foster particular kinds of subjectivities (see also section 4.9).

But in the passage quoted above, Cherry suggested that she did not arrive all at once at the position of someone who is able confidently to problematise the orthodoxies of social psychology. She described her annoyance at not being able to fit into the social space created by the academy. Reading this I reflected on my own experiences at university and in my clinical training. It

seems to me that Cherry was describing two aspects of the experience of not 'fitting in'. On the one hand the outsider feels frustrated and left out, perhaps she questions her own value, as it is measured by the establishment that she feels alienated from. On the other hand she is free to comment and criticise, to point out the inconsistencies and injustices perpetrated by the monolith that cannot accommodate her.

It is this 'locating oneself on the outside' that is the starting point for the social constructionist enterprise. Berger and Luckmann's (1966) work, *The Social Construction of Reality,* presented an early account of social phenomena as created and sustained through social practices. Though aspects of social life have come to seem 'natural' and inevitable, Berger and Luckmann argued that social practices and institutions derive from people's constructive work and interactions. Burr (1995), building on Gergen's (1985) framework has elaborated the underlying principles of the social constructionist approach which have particularly influenced social psychology. The first of these was *'a critical stance towards taken-for-granted knowledge'*, particularly knowledge about human nature and social life (Burr,1995: 3). On a fundamental level, social constructionism challenges the idea that aspects of the (social) world that we assume to be 'normal', 'obvious' and 'everyday' should be uncritically accepted as such. Using this approach we challenge the idea that there is a one-to-one correspondence between the labels we give to phenomena, and what is 'really there'. For instance we assume that using the word 'adolescent' will describe a relatively clearcut stage between childhood and adulthood. However, the term itself is of fairly recent historical provenance, as is the idea that such a distinct stage of human development exists at all (see Caldwell et al., 1998 for a cross-cultural and historical survey of social constructions of adolescence).

This example draws attention to the historical and cultural specificity of the ways in which we understand the world. The social constructionist approach

claims that ways of understanding are rooted in particular historical and cultural frameworks, and arise from the social and economic arrangements prevalent at the time. This generalisation extends to scientific and psychological knowledge as well. This means that claims that social scientists are able to use value-free ahistorical methodologies to uncover objective and unbiased truths about social reality are to be treated with scepticism.

Social science 'findings' can therefore be viewed as artefacts of institutional arrangements of a particular place and time, which reflect the prevalent social and economic arrangements of that society. These institutional arrangements will be more inclined to accept and propagate particular voices and viewpoints compared to others. Researchers are expected to 'fit the mould', and forms of social control may be brought to bear on those who do not. Cherry (1995) mentioned the casually sexist remarks she heard floating around her departmental meetings; Kitzinger (1987) reported being warned that she would be risking her academic career by studying lesbianism. In my own experience at university studying history I found that the topics relating to women's history which seemed to reflect my own growing feminist awareness were simply absent from the syllabus.

How do forms of knowledge then come to exist, if they do not arise as a record of what is 'really there'? Social constructionism suggests that knowledge is created and sustained through social action. Thus, our gender identity would not be seen as an intrinsic, natural part of us; we 'do gender' in our lives through our social practices. For instance, Scior (2000) suggested that women with learning disabilities are keen to stress their skills as homemakers, as a way of claiming a female identity that has been denied to this group of women in the past (who have been portrayed as genderless and axsexual. (See Burns, 1993)

> *Participant Three: I stay here today. I stay here all the time doing things around the house, like cleaning, washing, washing up, ironing, peeling potatoes, shopping. I'm good at making coffee, right? I'm good at making coffee and tea. Good at packing dishwasher, wiping tables and hoovering and dusting. Really* (Scior, 2000: 8).

From this perspective, gender identity is dynamic, it is negotiated through social interaction, and therefore potentially mutable and circumstantial. Social construction therefore turns our attention to the processes through which meaning is achieved. Language in particular is of great interest to social constructionists. Language is seen as a key site for the generation of meanings. People are seen as skilled language users who employ various devices to get their meanings across. This is rhetoric - the use of linguistic devices to persuade others of the power of one's claims to meanings.

However, discourse analysis is itself not a unitary approach, and there are proponents of discourse analysis who would not necessarily take the very critical approach to the theoretical approaches of mainstream psychology avowed by Hollway (1989) and others. Since the 1980s discourse analytic approaches have made considerable headway in psychology and have attracted enough adherents to coalesce into different 'traditions' (Wetherell et al., 2001). These different 'traditions' can be distinguished by the specific academic backgrounds of their proponents, whether in psychology, linguistics, sociology, or ethnology; by their favoured research topics, and by their particular orientations to matters of epistemology and political involvement. Wetherell (2001) outlined six more or less distinct discourse traditions; namely conversation analysis and ethnomethodology; interactional sociolinguistics and the ethnography of communication; discursive psychology; critical discourse analysis and critical linguistics; Bakhtinian research and Foucauldian research.

Since my background is in psychology, I have been most influenced by what Willig (2001) has identified as the two dominant trends in discourse analysis

that have had the most to say about the traditional subjects and objects of psychological inquiry such as identity, difference, social relationships and subjectivity; namely **discursive psychology** and **Foucauldian discourse analysis**.

4.3 Discursive psychology and Foucauldian discourse analysis

Discursive psychology (Potter and Wetherell 1987; Edwards and Potter, 1992; Potter, 1996) has been informed by developments in conversation analysis and ethnomethodology. Its focus of interest is how we use aspects of language to achieve interactional goals in local, everyday settings, particularly managing matters of stake and interest (Potter, 1996). People are seen as having a range of taken-for-granted interpretative and interactional competencies (Miller, 1997) which offer opportunities to 'perform' different activities through language, such as convincing, assigning or evading responsibility or blame, maintaining 'face' and status. It is through using these 'discursive resources' that versions of social reality are constructed 'from the bottom up' (Miller, 1997). With reference to my research questions, a discursive psychology approach addresses how my participants use the available discursive resources to build up representations of parents with learning disabilities and justifications of professional involvement with them.

Around the same time that Potter and Wetherell were challenging social psychologists to review what they could claim to know about language, cognition and social interaction, another group within social science, including psychologists, sociologists, and educationalists, was exploring ways of transforming the insights of Michel Foucault and other post-structuralists into a methodology to critically examine social and psychological life through the analysis of a range of 'texts', including written and spoken language (Henriques et al., 1984; Parker, 1992). Foucault's studies of prisons,

asylums, medical practices and sexuality (Foucault, 1965, 1973, 1977, 1981) described how ways of understanding ourselves (knowledge) and social relationships involving dominance and control (power) are inextricably intertwined, and enacted and reproduced in discourses. Foucauldian discourse analysis examines how we draw upon and position ourselves within discourses which are to some extent 'ready made'; they constitute the discursive economy of a culture, and often are so entrenched in everyday life as to seem simply 'common sense' (Fairclough, 1992). In this chapter I present a brief overview of how key Foucauldian concepts have come to constitute a discourse analysis methodology. I provide a more detailed description of the theoretical concepts in later chapters as they relate to themes identified in the analysis of my interview data.[1]

Of particular relevance to this study, which examines professionals' talk, Foucauldian discourse analysis is concerned with the relationship between discourses and institutions and institutional practices and the ways that cultures organise, regulate and administer social life (Willig, 2001). Parker (1992) argued that an important role for discourse analysis is to look at how institutional practices emerge historically through discursive practices, and to identify how institutions are reinforced or subverted through particular discourses. From the perspective of my research questions, a Foucauldian discourse analysis approach explores how different understandings of parents with learning disabilities link with discourses and institutional practices which facilitate or constrain different ways-of-being and ways of experiencing the world for the parents and for the professionals themselves.

These two discourse analysis approaches seem to me to be most productive in addressing my research questions. Though there is considerable overlap in these approaches, there are also significant differences between them in

[1] I describe Foucault's conceptualisation of different forms of power and their relation to knowledge and discourse in Chapter 10, and expand on issues relating to resistance in Chapter 12.

terms of epistemological positions, favoured research methods and topics (Willig, 2001). However, in line with Wetherell (1998) and Miller (1997) I suggest that different discourse analysis approaches can be used in complementary ways to illuminate different aspects of the research data and foreground different facets of the research questions.

4.4 Key processes in discourse analysis

First I identify some of the key processes involved in the discourse analysis approaches that I am interested in because they provide useful 'ways in' to my research questions. The headings have been suggested by the six stages that Willig (2001) advised as procedural guidelines for the analysis of discourse, and have much in common with Parker's (1992) twenty steps in the analysis of discourse dynamics. The six stages that I describe do not constitute a rule-bound approach to analysis, and will not necessarily be used in the order given below.

In addition to the outline below I explore methodological issues further in the data analysis chapters at the points at which particular discourse analysis procedures come to the fore.

*4.4.1 **Stage One:** identify different ways in which the discursive object is constructed*

The researcher identifies what she is interested in exploring, and explores how these objects are constituted within talk. The key focus of my interest is 'the parent with learning disabilities', and how this discursive object is constructed by human service professionals.

In this research I aim to identify the discourses that relate to three key sets of constructions. The first set of constructions is about learning disability. Typically such constructions address the definition and aetiology of learning

disabilities, locate people with learning disabilities with reference to 'normal' people, and seek to describe the goals of services and institutions that care for, support or control people with learning disabilities. The second set of constructions is about parenting and addresses issues such as the goals of parenting, the relative values of these different goals, the definition of the factors which block or facilitate the achievement of these goals, and the attributes of fit and unfit parents and the nature of childhood and children. The third set of constructions relates to the professionals who work with these parents, the scope and nature of their work.

*4.4.2 **Stage Two:** locate discursive constructions within wider discourses*

On another level, the discourse itself is constituted as an object through discourse analysis (Parker 1992). An important characteristic of a discourse is that it is systematic; its elements cohere in such a way as to achieve effects.

> *A discourse refers to a set of meanings, metaphors, representations, images, stories, statements and so on that in some way together produce a particular version of events* (Burr, 1995: 48).

That is not to say that discourses have to have watertight internal coherence, with all the elements in agreement with each other. Billig et al. (1988) have emphasised the way that thinking is dilemmatic, that there are elements in accounts that are contradictory and conflicting. On occasion these contradictions or dilemmas are overtly acknowledged by the speaker, which may have the rhetorical effect of enhancing the perceived reasonableness of the speaker (who is able to see both points of view), whilst allowing the speaker to appeal to the widest possible audience.

However, Billig et al. (1988) have pointed out that in other cases the dilemmatic aspects of the discourse are implicit; they are contained with the

semantic structure of the discourse itself. An example might be the discourse around 'people with learning disabilities and challenging behaviour'. On the one hand this concept gained currency as an attempt to emphasise that individuals behaved in socially unacceptable ways because of the lack of responsiveness and opportunities afforded them by their environments (Cullen, 1999; Emerson, 2001). On the other hand, 'challenging behaviour' has become an attribute that an individual can possess (people *with* challenging behaviour), and a key service response to this group has been to establish specialist and separate services and teams, with changes in the individual's 'level of challenging behaviour' as the key outcome variable.

Taking 'the parent with learning disabilities' as my key discursive object, I aim to investigate how this is constituted through discourses relating to parenting, disability, and human services, among others. My feeling is that 'the parent with learning disabilities' as a discursive object has a particular catalytic power. As an object, this concept is created within discourse, but I think that it also affects the structure and character of the discourse itself, in highlighting difficulties and contradictions and dilemmas occasioned by the discourse.

An area of controversy here is how far the discourse analyst may go in relating what is happening in the text under consideration to 'wider discourses'. Discursive psychology (Edwards and Potter 1992) requires that the analysis only touches on culturally available discourses in as far as they are referenced and discursively employed by the speakers of the text. This principle relates to what has been identified as a fundamental limitation of discursive psychology; its failure to account for why particular individuals or groups pursue particular discursive objectives (Willig, 2001). For instance, why are some attributes, social identities or positions preferred and other dispreferred? The answer to this question is further gainsaid by the reluctance of discursive psychology to look outside the text at the wider social

context as a way of illuminating why particular ways of representing the self carry authority or prestige and others do not.

By contrast, other writers, such as Parker (1992) and Hollway (1989) who might be grouped together into the 'Foucauldian' school of discourse analysis have been prepared to look beyond the boundaries of the text to the 'discursive economy', or the resources that exist within culture for people to use. They have contended that in order to understand the use of a particular discourse in a particular context, the researcher must be aware of social and material structures and the way that they are customarily enacted in particular discursive and non-discursive practices and rituals. Parker (1992) has further asserted that key features of discourses are those that relate to institutions and power relations. Therefore, at points during the writing up of my analysis of participants' talk I intersperse accounts of the institutional context which relate their constructions to wider organisational preoccupations, shaped by specific social and material concerns.

*4.4.3 **Stage Three:** pay attention to the discourse's action orientation*

Although I said in the section above that a discourse becomes constituted as an object through discourse analysis, I would not want to remove the discourse as an object for study in its own right from the people who actually employ it, and the context in which it is used. People do not use discourses in order for them to be abstracted out from their speech and examined by discourse analysts. They use them to bring off various accomplishments through their talk, for instance to blame, excuse or justify. The question here is what gain, in terms of social and interpersonal objectives, accrues to the speaker in using a particular construction at a particular point in the text (Willig, 2001). This aspect of discourse analysis, which Heritage (1984) has labelled its 'action orientation', has been expanded by Edwards and Potter

(1992) into their Discursive Action Model, which emphasises the performative qualities of discourse.

> *The focus of analysis for discursive psychology is on what people do with their talk, rather than using discourse as a way of accessing what goes on in their minds* (Horton-Salway, 2001: .153).

In this study I ask professionals about their work. I do not anticipate that their accounts represent a straightforward retrieval of information about their practices and the experiences of parents with learning disabilities. Speakers craft their talk in order to accomplish a wide variety of social actions. An invitation to talk about one's practice as a professional is likely to be heard as an opportunity to justify and account for one's actions, while fending off competing accounts which might result in losing face and authority. One aim of this study is to understand how participants discursively construct 'parents with learning disabilities' as the objects of their talk in specific local contexts. How might particular ways of describing parents with learning disabilities and one's professional interventions achieve desired interactional outcomes? Attention to questions like these help us understand how some ways of talking about parents with learning disabilities gain currency as the means to achieve social goals.

*4.4.4 **Stage Four:** identify the subject positions offered by the text.*

As Parker (1992) has pointed out, a discourse is about objects, but it also contains subjects, namely individual identities that are 'called forth' by the terms of reference of the discourse: '*a discourse makes available a space for particular types of self to step in*' (Parker, 1992: 9).

Subject positions may be thought of as circumscribed 'slots' (Burr, 1995) which we occupy, and which are limited in number by the discourse. For instance, prevalent discourses on disability contain the positions 'tragic victim'

and 'plucky survivor'. In actual verbal interaction, the subject positions offered by the discourse can be accepted or refused by the participants. To accept a subject position entails certain consequences in terms of the moral obligations and speaking rights defined by the discourse.

Burr (1995) points out how this conceptualisation is similar to Althusser's formulation of ideology as something that hails us ('interpellates') as a particular kind of subject. Once we become alert to this summons, we are constrained to listen in a particular kind of way, as a particular kind of person, who has particular speaking rights and responsibilities. As Davies and Harre (1990) explain, a subject position *'incorporates both a conceptual repertoire and a location for person within the structure of rights for those that use the repertoire'* (Davies and Harre, 1990: 283).

It is the 'structure of rights' which Davies and Harre (1990) associate with the subject positions available that define the possibilities and limitations of what we can do and who we can be within the discourse.

Drake's (1996) critique of traditional charities, for example, identifies the sorts of subject positions made available to disabled people in the charities' fundraising advertising and publicity. Charities contend that disabled people have impairments that are undesirable, represent a personal tragedy, and give rise to 'special needs', not shared by the general population. Whereas disabled people are positioned as needy, disadvantaged, and both wanting and requiring public support, the 'general (non-disabled) public' is positioned as under a moral obligation to help those less fortunate. Moreover, the general public is held to be effective in bringing about material change in the lives of the target disabled group, by means of financial donations, through the expert offices of the charitable organisation, of course.

In a more extreme post-structuralist formulation, the individual is seen as defined and constituted through socially constructed discursive positions. Readings of Foucault, for instance, often suggest that subjectifying power which creates particular kinds of individuals (power/knowledge) is ubiquitous and commands required practices through seemingly trivial microtechnologies (the timetable, the patient's dossier) which enforce social norms (for a more detailed exposition of Foucault's categorisation of different forms of power and their effects see Chapter 10, Section 10.2).

Although Foucauldian accounts do leave space for the possibility of resistance against seemingly hegemonic discourses (see Chapter 12), there is a tendency for Foucauldian discourse analysis to pose problems in terms of human agency – individual choice and intentionality. Davies and Harre (1990) therefore emphasise the way that subject positions are locally produced, negotiated and resisted by speakers in social interaction. The individual is characterised as a skilled language user who constantly (perhaps largely unconsciously) monitors the available subject positions that open up in social interactions, assesses the implication in accepting or resisting them, and exercises choice and makes decisions.

4.4.5 ***Stage Five:*** *examine the implications for practice*

The aim here is to map possibilities for action occasioned by the discourse, and explore which non-verbal practices are expected by the discourse and the subject positions it offers, and which are constrained or forbidden.

This link between discourses and the sorts of activities they might support or constrain is one of concerns of systemic family therapy, which has drawn theoretical inspiration from some of the concepts of social constructionism (Dallos and Draper, 2000). For instance, in their systemic family therapy work in a community learning disability service, Baum et al. (2001) noticed that

some parents of adults with learning disabilities positioned themselves as 'perpetual parents' (Todd and Shearn, 1996). Their key role in life was to stay on hand to care for and look after their son or daughter. This positioning would facilitate practices like restricting their social contact to other parents of adults with learning disabilities. It would close down other possibilities for action, such as spending time alone as married couple, or entrusting the care of their son or daughter to others.

Subject positions such as these give us cues about the sorts of social actions that are appropriate for the people who occupy these slots and the sorts of moral claims we can make for our actions. Inasmuch as discourses are about power relations, these positions also accord us our measure of power or powerlessness within the social order. In this sense, the process of discourse analysis can suggest which category of person stands to gain, and which to lose from the use of the discourse, and the practices it promotes or restricts (Parker, 1992).

An example of this last point is the position occupied by men and women within the male-sexual-drive discourse discussed by Hollway (1989) in her analysis of heterosexual relations. This discourse suggests that male sexuality is characterised by irresistible sexual urges which demand satisfaction. Use of this discourse can allow men power to 'call the shots' in sexual encounters, and it has even been used in court cases to excuse rape and sexual assault.

However, the position of the woman within this discourse is not completely that of powerlessness. It is the woman who triggers the man's sexual response by acting or dressing provocatively. The woman has power in that she is able to unleash the man's sexual feelings. Once this has happened, the man loses control, and falls victim to his urges, and the woman's capacity to satisfy or deny him.

Researchers such as Hollway see discourse as primary, in that discourses facilitate or restrict possibilities for action. Willig (2000) has pointed out that there has been less research into the ways that practices, especially regulated and institutional practices, may limit the sorts of discourses and subject positions that can be accessed. She quoted Harre and Gillett (1994):

> *...to act with freedom, the discursive possibilities that are potentially available to an individual must be affirmed, owned and used in some practice.*

Social and material practices, linked to institutions and power, make some meanings possible and provide access to some subject positions and not others. As an illustration of this point I would like to draw attention to the way that communications between people with learning disabilities and representatives of the welfare state are shaped and constrained by the structure of case conferences. Case conferences have been studied by Marks (1996a, 1996b) and her insights strike a chord with my own observations of child protection conferences, that conferences are imbued with institutional power, which position people with learning disabilities as having problems and needs. They create a context where these are the only discursive resources available to people with learning disabilities. I have noticed that when a mother with learning disabilities that I know tried to talk about her competences and skills, the conference fitted this into a discourse of 'denial of difficulties', which created further evidence against her suitability as a carer for her children.

In this study I am interested in the possibilities for professional practice provided by the discourses employed by participants. Research with parents with learning disabilities themselves suggests that they can clearly articulate the sorts of services they want, (Booth and Booth, 1995; Strike and McConnell, 2002) but also charts the gaps between these aspirations and what they experience of professional support (McConnell et al., 1997;

Llewellyn et al., 1999; Guinea, 2001). As mentioned in Chapter One, it is an aim of this study to investigate how discourses relating to parents with learning disabilities contribute to a situation where the scope for progressive and supportive professional practice seems to remain limited, and where accounts of discriminatory and oppressive practice seem depressingly familiar.

*4.4.6 **Stage Six:** consider how the discourse shapes subjectivity*

Hollway (1989), Parker (1992) and other proponents of discourse analysis influenced by Foucault and psychoanalytic theory (especially Lacan) are particularly interested in how subjectivity, the experience of being a person and having self-awareness, is discursively created. They question the concept of the fixed, unitary subject, who is defined in contradistinction to the social sphere, which is the focus of much psychological enquiry.

> *[S]ubjects are dynamic and multiple, always positioned in relation to particular discourses and practices and produced by these – the condition of being subject* (Henriques et al., 1984: 3).

Taking up a particular subject position, therefore, will have consequences not only for what can be said and done, but also for what can be felt, thought and experienced. Questions of subjectivity, involving our sense of self, intentionality, self-awareness and autobiographical memories, go beyond the remit of Discursive Psychology. However, thinking about subjectivity and how it is produced through discourse, may address one of the inherent limitations of Discursive Psychology mentioned earlier – its problems with accounting for *why* speakers pursue particular discursive objectives (Willig, 2001). Given that multiple, sometimes contradictory discourses can co-exist, what leads people to take up positions within one discourse, rather than another? Hollway (1989) using insights from Lacanian psychoanalysis, has suggested

that the reasons may be hidden, even unconscious, motivated by desire and linked to access to power.

Sinason has drawn our attention to the ways that descriptions of people with Down's Syndrome often emphasise their 'happy' and 'loving' nature. She suggested that this 'racist' myth (Marks, 1999b), akin to the idea that fat people are 'jolly' and carefree, is a defensive denial of the knowledge that the lives of many people with learning disabilities are painful and unfulfilled;

> *[t]he strength of the desire to make the immigrant, the handicapped, the fat or the ugly smiling and cheerful unerringly covers our precise knowledge of the opposite* (Sinason, 1992: 28).

Persisting in this defensive discourse confirms those of us who are 'normal' in our belief that disabled people are intrinsically and essentially different, that they do not experience discrimination and injustice. This emphasis on the 'otherness' of disability protects us from our feelings of confusion, fear and sadness confronted by people who are different and suffering as well as our own our own feelings of 'stupidity' and ignorance in the face of these difficult emotions.

Marks (1999a) also suggested that being positioned within the discourse of the 'happy handicapped' has consequences for the subjectivity of people with learning disabilities themselves. She raised the question whether this positioning prevents people with learning disabilities from developing a sense of entitlement, a feeling that they deserve more than exclusion or at best charitable hand outs tailored to the expectations of a disabling culture. The anger and despair provoked by institutionalised discrimination may instead by channelled into self-injury and futile outbursts that are labelled 'challenging behaviours'.

4.5 Using discourse analysis

Discourse analysis as a method does not come with a toolkit of procedures. Whereas experimental psychology insists on conventions which have been formalised over decades of academic production, such as random selection of participants, including the number of participants required by statistical analysis, double-blind trials, use of standardised tests and instruments, discourse analysis is a method that is still developing and changing.

The key resources that I had at hand to work on in my analysis were the written texts which are the transcription of my interviews with professionals, and my own knowledge, experience interests and preoccupations, which were continually available to me and reflexively noted in the process of analysis.

My overall aim is to highlight the social constructions created in the discourses of the participants in order to address my research questions relating to learning disabilities and parenting. Potter and Wetherell (1987) have suggested that the activities researchers should engage in are coding and analysis.

Coding: Potter and Wetherall have written that the goal of coding is to '*squeeze an unwieldy body of discourse into manageable chunks*' (1987: 167). The question here is, of course, what are the categories into which the data should be chunked? Potter and Wetherall answered that the categories should be '*crucially related to the research questions of interest*'. Sometimes this can be done by identifying a key word or key concept and selecting all references that seem to connect with these.

In practice, I identified three very broad areas of interest. The first was around 'learning disability' and I read through the transcribed interviews

looking out for ways that participants characterised the parents they knew as 'people with learning disabilities'. In some interviews I had asked for and received 'definitions' of learning disabilities (explicitly asking a question like 'what does the term learning disability mean to you?). I was also interested in how participants described parents behaving in a certain way 'because of' their learning disability, or descriptions of what parents with learning disabilities 'generally' do, or how the category of 'learning disability' was invoked to justify or explain some activity of the participants themselves. I abstracted out a section of the text and put it in a computer file under a name that was an attempt to pin how 'learning disability' was being constructed, or how the construction was being used (names like 'DENIAL', 'IQ', 'CHILDLIKE'). As I read the next interview I looked out for further examples that seemed to fit into the files I had already created, and went on to create more (sometimes then doubling back to interviews I had read earlier where I felt I had missed more oblique references to similar constructions or arguments).

After that I began the process of analysis/interpretation and writing up (described above and below), before moving on to the next area of interest.

The other two areas of interest were around children and parenting, and around professionals and their practice. For each I went back to the transcribed interviews, reading them through again and looking out for explicit or implicit references to these constructs, and collecting the chunks of text in data files. At this stage the chunks of text were quite long, to preserve a sense the context in which a construction or argument was being offered. Though sometimes the process of compiling data files with chunks from lots of different interviews seemed to lose something important; a sense, not of the generalisations that can be gleaned from the different texts, but the flavour of the individual accounts, and the shape and sense of the particular narrative that each constructs. Also to focus on one account may make it

easier to identify contradictions and conflicts within the discourses that the speaker references. Speakers themselves may present different sides of an argument, or attempt to reconcile contradictions in their accounts. The chunking exercise on the other hand, may obscure these contradictions **within** accounts, whilst highlighting differences **between** accounts.

Interpretation and writing up When it comes to describing the 'how to' of analysis, Potter and Wetherall admitted to some serious difficulties. *'Words fail us at this point'*, they say (1987: 168), not very helpfully; *'it is not a case of stating you do this then you do that'*. However, they did venture some guidelines, which I referred to after completing most of the coding process, and in conjunction with the different 'stages' of discourse analysis described above:

a. Careful reading and rereading of texts.
b. A critical examination of our own techniques of sense making.
c. A search for pattern in the data - looking both for similarities and differences between accounts in terms of both form and content.
d. Forming hypotheses about the functions and effects of the accounts and looking for the linguistic evidence that backs this up.

It was this process of hypothesis formation and testing which formed the starting point for my writing up. As I have argued earlier, the task of discourse analysis is not only to describe how knowledge is constructed, but also to attempt to explain how and why particular understandings are proffered in particular contexts. I found the best way to explore my hypotheses was in the actual process of writing up, taking each of the areas of interest in turn. At the same time I was doing the writing up, I was reading from secondary sources and contrasting and comparing my participants constructions with those advanced in the academic literature. I found this process most useful particularly when I was considering the link between my

participants' constructions and wider discourses, or locating socially prescribed 'subject positions', or looking for links with contemporary ideology or institutions. I found myself interweaving these different sorts of accounts in writing up, in a way that is perhaps unusual in social psychology research, especially when I found myself journeying into areas of social science, such as sociology, social theory and ethnology, situated far from my own 'home disciplines' of clinical and social psychology.

4.6 Reflexivity

I opened a discussion on reflexivity in my introductory chapter, where I distinguished between different meanings given to the term. At that point I focused more on personal reflexivity, which I defined as the researcher's acknowledgement and reflection on her own experiences, values and politics insofar as they might guide the inception of the research, the research questions and the interpretation of data. I would like here to explain the importance of epistemological reflexivity, *'the way that theory is applied to itself and its own research practice'* (Burr, 1995: 180).

Again, there are different levels at which the concept of epistemological reflexivity can be put into practice. There is reflexivity at the level of interpretation, whereby the researcher investigates her methods of constructing the research report as an authoritative text (Alvesson and Skoldberg, 2000), by looking at her use of language and rhetoric, at the way that she selects certain passages and voices to construct a particular reading of her data. From this perspective the researcher cannot profess to have unearthed 'findings'; her report constitutes a text in which puts forward certain truth claims, but which is nevertheless only one reading abstracted from a number of possibilities.

I am also interested in the form of reflexivity suggested by Wacquant and Bourdieu (1992: 39); challenging what they call the 'intellectualist bias' of social science. This involves the researcher critically examining the presuppositions and limitations of her own academic discipline and being able to step back from its frame of reference (Alvesson and Skoldberg, 2000), allowing for a pluralism in theory and methodology;

> *What has to be constantly scrutinized and neutralized, in the very act of construction of the object, is the collective scientific unconscious embedded in theories, problems, and (especially national) categories of scholarly judgement* (Bourdieu and Wacquant, 1992: 40, emphasis in original).

One presumes that each discipline has its own 'collective scientific unconscious' (Bourdieu was particularly interested in the development of sociology in France following the *evenements* of 1968), but the authors also suggest that in general terms the 'intellectualist bias' encourages researchers to avoid engagement with their material at a political and practical level, since it

> *entices us to construe the world as a spectacle, as a set of significations to be interpreted, rather than as concrete problems to be solved practically* (Bourdieu and Wacquant, 1992: 39, emphasis in original).

I interpret this statement as an injunction to researchers not only to orientate themselves to an appreciation of their data as representative of real-life, lived experience, but also to move beyond a critical commentary on the phenomena they are examining, and involve themselves more actively with issues of social and political practice. Such activities are not without their own pitfalls (Willig, 1999). I examine these further in my final chapter, where I explore the opportunities for change at the level of practice, suggested by my research.

Whereas in most quarters qualitative researchers are encouraged to aspire to a fully reflexive stance, many of us remain unsure how to operationalise these

aspirations, and there are those who question whether thorough going reflexivity is either possible or desirable. The objections to such a project can be summarised as risks involving 'narcissism, futility and *regressio ad infinitum*' (Bourdieu and Wacquant, 1992: 43). It is with these hazards in mind that I conclude my reflections on reflexivity in my final chapter.

4.7 Conclusions to Chapter Four

In this chapter I have described some of the theoretical underpinnings of discourse analysis, and described how it may be used as a method in the analysis of texts. In doing so, I have drawn from a variety of approaches in discourse analysis, while at the same time acknowledging some of the debates and difficulties that exist within different approaches. I have explained why discourse analysis is the most appropriate way to 'interrogate' my data set so that it responds to my research questions, which are about how knowledge about parents with learning disabilities is created and how this knowledge influences practice. I intend that the relationship between my methodology and my data remains a dynamic one, so that findings from the data can inform analytic practice, while acknowledging how discourse analysis as a theory and method, can shape what can be known and said about the data.

Chapter Five: Data Collection

5.1 Introduction to Chapter Five

In this chapter I clarify my reasons for interviewing professionals, rather than parents, exploring some of the ethical and practical issues implicated in doing research with parents with learning disabilities and the people who work with them. I describe how I contacted participants, and provide information about who actually took part in the research interviews. I outline some of the theoretical concerns that guided the way that I approached the research interviews and list my interview questions. Finally, I look at research ethics more broadly, not only the safeguards needed to protect participants, but also the specific issues relating to power and authorship raised by discourse analysis.

5.2 Research participants

In this section I will develop further the issues raised by way of the question at the very beginning of the study; 'why does this research focus on what professionals say?' I am particularly aware that my decision not to use the words of parents with learning disabilities themselves can be seen as contributing to the exclusion of their voices and perspectives from academic accounts. Such exclusion may also be seen as reinforcing assumptions that

people with learning disabilities lack the ability to speak for themselves, as well as denying them opportunities to contribute to research practice and the recommendations for service developments which often spring from research.

Nevertheless, I have chosen to collect data for this research only from professionals who work with parents with learning disabilities. To counter the criticism suggested above, that deciding not to interview parents themselves implies a devaluing of their communicative abilities, my decision did not come about because I think that people with learning disabilities would not be able to contribute sufficiently to a project using discourse analysis, which would be dependent on the production of largely verbal data[1]. Scior (2000) for instance, presents an illuminating and convincing example of discourse analysis work with women with learning disabilities. Like the rest of us, these women with learning disabilities were able to access elements of the 'discursive economy' relating to sexuality, relationships and gender roles (see also Rapley (2004) and Yates (2005) for further recent examples of conversation analysis and Foucauldian discourse analysis of accounts by people with learning disabilities). My concerns are more ethical and practical. My clinical work has given me an insight into the great amount of stress that parents with learning disabilities experience in their lives partly related to living in what are often very disadvantaged circumstances with limited support, and partly related to their contact with professional services. Although services might see themselves as supportive and enabling, there is often a monitoring and evaluative element to their interventions. Contact with a researcher is likely to be perceived by the parent as yet another demand from a professional on their time and overstretched resources, with no obvious benefits accruing from this.

[1] Although Booth and Booth (1996) acknowledge the difficulties that some people with learning disabilities may have in expressing themselves verbally. These 'inarticulate subjects' accounts may need to be supplemented by observations, accounts from friends, supporters and family or written documentation.

As well as feeling intrusive and possibly judgmental, asking questions of a parent with learning disabilities about their experiences of family life and services may raise some painful and unresolved feelings. People with learning disabilities may be reminded of their experiences of loss, discrimination and social exclusion in interviews about their lives (Alderson 2000) and for some parents this might mean recounting very distressing experiences of their children being removed into local authority care.

It is likely that parents that I would invite to participate in the research would already be 'known to services'. In some cases I would be operating in an environment where child protection issues were already live. What would be the limits of confidentiality between me and the parent as research participant in this context? Would I be expected by services working with the parent to report any 'concerns' about the children in the household related to definitions of neglect or abuse that I picked up in my interviews?

On a practical level, getting to know a parent with learning disabilities, establishing a relationship of trust with someone whose experiences of professionals might well have been negative, finding opportunities to talk and reflect away from the demands of children, partners, friends and service providers is not an impossible task, but one that requires a great deal of time and flexibility from a researcher. It also requires a renegotiation of the huge power differential between the researcher and the person with learning disabilities. When the Booths (Booth and Booth, 1994) embarked on their research with parents with learning disabilities, they soon found that they entered into a relationship with the parents in their study on many levels, as a confidant, advocate, helper, and friend.

It is with some regret that I acknowledge that people with learning disabilities in this study are talked about rather than talking subjects. However, the fact that their presence is felt primarily in the accounts of the professionals who

describe them makes it clearer that to be a 'parent with learning disabilities' is a socially constructed identity and one which these parents themselves would not necessarily adopt. Moreover, one could argue that the very label 'learning disabilities' derives more from the bureaucratic and economic concerns of the welfare system than a clear cut, uncontroversial set of attributes possessed by an easily quantifiable set of individuals.

On a personal level my decision to focus on professional accounts springs from my own identity and experiences as a learning disability professional. Working with parents with learning disabilities has often left me feeling muddled and confused, and talking to other professionals has to some extent given me opportunities to think about my own ideas and approaches to this work in discussions with participants who to varying degrees constitute an assembly of my peers.

Moreover, focusing on professional's talk based on their actual everyday experiences with parents with learning disabilities 'fills a gap' (Silverman, 2005) in the research literature. Accounts which foreground the experiences of parents with learning disabilities and which give them opportunities to represent themselves 'in their own words' are thankfully becoming more common (Booth and Booth, 1994, 2003a; Strike and McConnell, 2002). These accounts often highlight the impact of discrimination and lack of sensitive support on parents' lives, and are critical of much of professional input. However, what is missing is what Tragaskis (2000: 344) calls 'the other side of the coin':

> *Namely, an investigation of the individual and collective ways in which non-disabled people's attitudes, beliefs and perspectives on disability and impairment are constructed and maintained.*

Tregaskis (2000, 2004) argues that researchers should acknowledge the role of non-disabled people's attitudes in perpetuating the exclusion of disabled people. Though I broadly agree with her, my standpoint from a

constructionist rather than a more empiricist 'attitudes' methodology leads me to assert that the exclusion of disabled people is actually constituted in the discursive practices of the 'psy-complex' (Rose, 1996), the workers in human services who define and monitor what becomes understood at normal and desirable in human attributes and behaviour. My interviews with professionals who work with parents with learning disabilities were sites where such parents become constituted. Furthermore, using a discourse analysis approach suggests ways in which professionals use discursive resources in order to justify and promote particular constructions of parents with learning disabilities, and to fend off others.

Conducting interviews with professionals who work with parents with learning disabilities meant that there was a more equal distribution of power between myself as a researcher and practitioner, and the participants in this study. I hope that this meant that participants felt that they have had the freedom and authority to consent to taking part in the study in the first place, as well as to a particular line of questioning. I also hoped that participants felt able to challenge my assumptions and the subject positions that I constructed within our interactions.

5.3 Finding participants

In this study, I used different methods to contact participants.

5.3.1 Postal questionnaire

After securing approval from the local ethical committee, I made a 'service map' of the services in three Inner London Boroughs that I thought might be in contact with parents with learning disabilities, such as midwives, health visitors, children and families social workers and workers in specialist services for people with learning disabilities. These London Boroughs were chosen because they constituted the geographical reach of the large NHS

Trust where I myself was employed, where I already had some understanding of local institutional structures and cultures, and which were practically convenient for me to travel to from work or home. I talked to eight service managers who had various responsibilities for midwifery and health visiting services, social services children and families departments and specialist learning disabilities teams, not-for-profit agencies providing housing and social care support for people with learning disabilities. We discussed the aims of the research and they confirmed that they were happy for me to contact their staff.

In a short questionnaire (see Appendix One) sent to team leaders to distribute, I asked the professionals in the various services if they had past or current experience of working with parents with learning disabilities, and whether they would be prepared to take part in a study looking at the professionals' views and experiences around doing this sort of work. I assumed that a number of these workers might not have a clear working conceptualisation of 'learning disabilities', so I enclosed a checklist (derived from Whitman and Accardo, 1990), which offered pointers to the presence of learning disabilities in terms of lack of skills, such as literacy and numeracy, support needs, and contact with specialist services. I am happy to admit that my operational criteria for recognising learning disabilities is a socially constructed artefact, and does not unambiguously reflect any 'essential attributes' of what it means to have a 'learning disability'.

In all, I sent 450 individual questionnaires, with attached stamped addressed envelopes to team leaders in health and social services for them to pass onto their staff, and to small agencies for people with learning disabilities.

The health services included hospital antenatal departments, community health care, child development centres, and multi-disciplinary teams for people with learning disabilities. The social services settings comprised Adult

and Children and Family Teams, Family Centres, as well as specialist teams for people with learning disabilities. The not for profit and charitable agencies provided residential support services as well as advocacy, counselling and training for people with learning disabilities.

5.3.2 Responses to the questionnaire

In total, I received 145 responses. The breakdown of professionals, who returned the questionnaires is represented in the Table I below, according to the occupations that they identified in their responses.

Table I Profession of respondents to survey questionnaire

Profession	**Number (N = 145)**	**Percent**
Health Visitor	67	46.2%
Social Worker	32	22.1%
Midwife	16	11.0%
Manager of not for profit or charitable agencies for people with learning disabilities	8	5.5%
Nurse	7	4.8%
Clinical or counselling psychologist	5	3.4%
Worker for not for profit or charitable agencies for people with learning disabilities (including advocates)	5	3.4%
Occupational Therapist	3	2.1%
Speech Therapist	1	0.7%
Housing Officer	1	0.7%

In response to the first question, "Have you ever worked with a parent who has learning disabilities", **79%** (115) of the respondents said "yes". **Fifty six percent** (81) of the respondents had worked with a parent with learning disabilities within the last 12 months, and **39%** (57) were still working with a parent with learning disabilities. Eighty Seven (**61%**) said that they would be

willing and able to be interviewed about their experiences of working with parents with learning disabilities.

The overall total response rate of this postal questionnaire was 32%. However, the response from the different boroughs was very uneven, with a particularly poor response from Social Services Departments in one borough. It is therefore very likely that results do not accurately reflect the number or types of professionals who were working with parents with learning disabilities in those London Boroughs at that time.

Of those who did respond to the questionnaire, a substantial majority had had contact with parents with learning disabilities. Most of the respondents were health workers, who would not have had specialist training in working with adults with learning disabilities. However, there was generally an expressed willingness on the part of respondents to have further contact with this research project, perhaps in the hope of receiving further support and information about this topic.

5.3.3 Contacting participants

Of the professionals who responded to my questionnaire and indicated that they were happy to meet me to be interviewed, I contacted a smaller group by phone, trying to arrange meetings with a few from each professional grouping. I was interested in talking to people who would have a range of professional roles and breadth of experience with relation to parents with learning disabilities and their children. For instance, children and families social workers were more likely to become involved only after fairly serious concerns had been raised about the welfare of children, and would be expected to foreground the wellbeing of children. Alternatively advocacy workers would focus their professional attention on their relationship with the person with learning disabilities, and would see their prime focus as supporting that person to have their voice heard and their choices respected.

From another perspective, for workers from generic services, people with learning disabilities would constitute only a small part of their caseload, and they were unlikely to have come into much contact with theoretical or practical approaches to working with this client group as part of their training. Workers from specialist learning disabilities services would be able to draw on much more extensive experience of this client group as a whole and would have had exposure to more background knowledge about learning disabilities' services. Thus in recruiting a selection of participants from different professional backgrounds, I was hoping to open possibilities to hear about different constructions of parents with learning disabilities and their children, and different positionings for professionals in relation to these parents.

I also asked people that I knew through my professional networks in the same geographical areas if they would be interviewed because I knew that they were working with parents with learning disabilities, even though they were not among the respondents to the original survey. Some of these people talked about parents who were already known to me through my clinical work. Others were people who I counted as good friends. The fact that I had these sorts of relationships with my research participants gave rise to particular discursive practices and negotiations within the interviews that I hope will be reflected in my analysis of this data.

Before meeting each of the participants, I sent them a short document explaining the research project, its aims, the process of doing the research, issues of confidentiality, and dissemination of findings (see Appendix Two). I described what I intended to do in the following words:

> *to talk with people who work with parents with learning difficulties from a range of different professional backgrounds, and find out about their experiences in working with these parents.*

I was careful not to characterise 'parents with learning disabilities' ipso facto as a social problem, needing exploration and solution. However, I did justify

the research by fielding an assumption that professionals feel challenged by the complexities involved in working with parents with learning disabilities and held out the possibility that the research feed back suggestions about professional practice:

> *People working with these parents sometimes find their work is quite complicated, often with lots of different agencies involved, and I am interested in finding out how workers make sense of their work and what barriers they may encounter. I hope that the findings from the project will help us do a better job of working with families with parents with learning disabilities. It might throw up some ideas about the sort of training or organisational change that would help.*

Looking at this passage retrospectively, with a critical, discourse analysis eye, I can see that I implicitly advance a relationship between theoretical research and its application, especially in terms of benefits to service users (*the findings...will help us*) which I presume potential recruits would be likely to view as worthy and commendable. Potter (1982) has critiqued the assumptions of social psychology that the 'application' of research findings to real-life problems and settings is smooth and uni-directional, whereas in practice, the practical application of theory is constrained by institutional, social, political, and economic interests. Perhaps in order to fend off criticism when my research fails to come up with any earth-shattering recommendations, and also in recognition that participants may feel quite nervous about being associated with critical conclusions, my use of tentative verbs, indefinite articles and conditional particles somewhat tempers expectations that I will use what participants say to be overly prescriptive ('*I hope...it might throw up some ideas about the sort of training or organisational change that would help*').

I also identified myself professionally as a clinical psychologist, working in a multi-disciplinary team for people with learning disabilities in London. I acknowledged that I did work with parents with learning difficulties as part of my contribution to the team in which I was based (a statement which claimed some commonality of experience with the potential participants). However I

did clarify that the research project was not part of my NHS work, and therefore had a status 'independent' of overt organisational interests.

As I explore in the later chapters analysing the interview material, my status as a clinical psychologist could not fail but to impact on the subsequent conversations which took place. I imagine that the following dimensions were particularly pertinent; my relatively high status amongst health and social care professionals (qualification as a clinical psychologist is a lengthy process, with strong links to academic institutions and discourses, and these days culminates in the award of a clinical doctorate, with commensurate financial rewards); my professional association with technologies of human measurement such as IQ tests; my assumed prowess as a 'sympathetic listener'; my insider knowledge of service structures, policies and relevant legislation.

5.3.4 Characteristics of research participants

Eventually I interviewed the following staff:

Table Two: Breakdown of research participants

Category of professional worker	**Number**
Learning disabilities social worker	1
Children and families social workers	4
Residential family centre workers	3
Workers for not for profit or charitable agencies for people with learning disabilities – service broker and family aid worker	2
Advocacy workers	3
Clinical or counselling psychologists	2
Health Visitors	5
Total Participants	20

I did not collect much biographical information about my participants, apart from how long they had been doing their jobs. All except for two were women. Years of experience ranged from 2 to 23 years. I did not ask participants to identify themselves as members of a particular ethnic group, though I would judge that about a third were from ethnic minorities.

5.4 The research interview

Discourse analysts gather data from a very wide variety of sources. Not only written or spoken language from interviews, academic texts, newspaper articles or naturally occurring conversations, but also photographs, films, buildings, landscapes, machines can be seen as 'texts', which Parker has defined as '*delimited tissues of meaning reproduced in any form that can be given an interpretative gloss* (Parker 1992: 6).

Derrida's (1976) aphorism is often quoted in this context; *'[t]here is nothing outside of the text'*. Patterns of behaviour can be seen as 'text' for analysis; Edley (2001) calls such behavioural patterns, 'discursive practices' through which individuals accomplish socially defined identities. For instance, watching football matches, carving the Sunday roast, driving too fast on the motorway, styles of dress and posture are ways that men 'do' masculinity. Such practices are not signs of an underlying masculine essence, they are ways that masculinity/masculinities are discursively constituted.

However, in this study, I restricted the focus of my inquiry to talk that occurs within the context of research interviews. A different option might have been to analyse portions of naturally occurring talk that might occur in staff team meetings, for instance, or Child Protection conferences. Research that has been undertaken in these sorts of settings (for example Marks, 1996b; Mehan, 1996) has explored the construction of learning disabled identities

through professional discourses. Nevertheless, there were a number of advantages in using the interview situation rather than observing professionals talking in meetings. First, I was able to make contact with a range of different professionals who would be unlikely to be found together in a real life situation. I was able, therefore, to access the accounts and constructions of a range of professionals who come into contact with parents with learning disabilities, such as health visitors, social workers, advocates, psychologists, advocates and family centre workers, who would have a range of perspectives and professional approaches. Second, equal time and consideration has been given to each of my participants' individual voices, whereas in meetings typically certain individuals 'hold the floor', whereas others contribute much less, or are even completely silent.[2]

Third, a research interview also allows for the active intervention of the researcher; she can question an entire sample on the same issues, thus allowing for comparisons between responses (Potter and Wetherell, 1987), raising questions and issues which would not come up in naturally occurring settings. A further point, which I have touched on before, is that in a discourse analytic interview, the researcher does not seek to erase her own presence or authorship from the interaction with participants. Potter and Wetherell (1987: 164) go so far as to say that the researcher's own contribution is important in *'...mak[ing] the interview a more interventionist and confrontational arena than normal'*.

The aim here is not to unearth the participants 'underlying beliefs', which should conform to some consistent pattern, but attend to variations and contradictions in responses and the diversity of accounting practices employed by participants. The researcher is present as an active participant

[2] Of course, exploring the speaking privileges and rights of different participants in meetings will contribute to an understanding of which discourses are dominant and which are suppressed in a particular setting (Mehan, 1996). When a participant is completely silent,

in this process, and her questions become as much a topic of analysis as the participants' answers.

No doubt due to my training in clinical psychology, there is much in my interviewing style that approximates to a 'person-centred counselling' mode of interviewing. My questions were open-ended on the whole, inviting reflections and 'depth' answers. I allowed my participants to pause and take their time over their responses. My contributions were often made up of **minimum response tokens** (Fairclough, 1992) ('hmm', 'right', 'yeah') and in my responses I attempted to be encouraging, supportive and to avoid criticism or the sense that there was a 'right answer'.

5.5 The interview questions

The interviews were not based around a predetermined set of questions which had to be asked in a particular order. My aim was to elicit stories concerning the participants' work with particular parents with learning disabilities. I was interested in the participants' understandings of concepts such as learning disabilities, the goals of parenting, the aim of professional interventions, as well as their explanations for their actions, and their evaluations of their interventions. The kinds of questions I asked were:

- Tell me about your work with a parent/parents with learning disabilities.
- What parts of the work did you enjoy?
- Which parts were difficult?
- What impact do you think the parent's learning disability has/had on how they bring up their children?
- How would you hope things turn out for this parent and this family?

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their non-participation may be read as a form of resistance (Marks, 1993), though this interpretation necessarily involves a good deal of speculation.

- Did anything in your training turn out to be helpful in the work you do with parents with learning disabilities?
- Do you think the fact that you do/do not have children yourself makes any difference to the work that you do with parents?
- Looking back on your intervention, would you have done anything differently?
- What sort of support do you get from your organisation to help you in your work with parents with learning disabilities?
- Do you think parents with learning disabilities need special services?

The interviews took place in the participants' workplaces and usually took between an hour and an hour and a half. At the end of the interview, participants were invited to raise any questions about the research, and also to reflect on the interview itself and talk about how it had felt answering my questions.

I collected the data for this study over a fairly extended period, between 1996 and 2002 and the writing up process continued over the next three years. This included time off for maternity leave and episodes when the research 'lay fallow' due to other commitments.

5.6 Transcription

All the interviews were tape recorded (with the participants' permission). Transcribing the tapes was a laborious business. I did try to capture some detail, in terms of length of pauses, repetitions, overlapping speech, emphasis, and some non-verbal utterances. Discourse analysts vary considerably in terms of how much detail they include in their transcripts (Taylor, 2001). My aim was to try to identify how such features can be meaningful in how we construct accounts. I wanted to look at how such features of interactions are employed rhetorically. However, I did not go into

the same degree of detail as might be found in conversation analysis, and therefore signalled my interest in the aspects of talk that are similar to writing, namely words, and the concepts that they express.

5.7 Ethical issues

5.7.1 Consent and privacy

Obtaining consent to interview participants proceeded through three stages, institutional, organisation and individual. I received permission to undertake the research from the ethics panel responsible for research projects in the NHS trust covering the three inner city boroughs where the participants were recruited. At the organisational level I wrote to and spoke to the service managers of the health, social services and third sector voluntary agencies to secure their support for the research before sending out the survey questionnaires and recruiting participants. In terms of securing consent from individual participants, when I spoke to the practitioners who indicated they were willing to be interviewed on the phone to arrange an interview date I explained the purpose and process of the research. I sent each participant a written outline to read before the interview took place.

All researchers have an obligation to protect participants from untoward intrusion and exposure. At the beginning of my interviews I discussed with participants issues relating to confidentiality, anonymity and non-traceability. I undertook not to use their real names or that of their workplaces or clients in the transcriptions and write-ups of their interviews, and no personal information was kept on my computer. Participants were at liberty to tell me if there were parts of the interview that they did not want to be recorded or to form part of the data to be analysed, though I made it clear that I would have to breach confidentiality if I was concerned that someone was being harmed.

In the illustrative extracts from the interview transcripts I have taken care to remove any personal details which might identify individual practitioners, parents or children. In accordance with the requirements of the 1998 Data Protection Act, no personal or identifying information was kept on my computer, and all tapes and notes were kept in a lockable place.

5.7.2 Power relationships in interviews

So far I have described the practical measures that I took in order to protect participants' interests as part of what are commonly seen as the ethical obligations on all researchers to prevent harm. However, there are more complex and subtle questions relating to respect and power which particularly apply to qualitative research interviewing which I will now consider in more detail.

First, negotiating consent should not be seen as a one-off activity which is achieved before the interview takes place. Participants should not feel pressured or manipulated into disclosing information during the course of the interview. As Jorgensen (1991) points out, there are asymmetric power relationships between the researcher, who asks the questions and the participant, who feels obliged to answer them (Grice 1975). In order to redress the balance somewhat, and bearing in mind Elwood and Martin's (2000) observation that power relations in research are spatially constituted, I met with participants in their own workplaces, where they were the resident 'experts' and I was the 'visitor'. Moreover, when we met I emphasized our shared identities and difficulties as practitioners.

However, D'Cruz (2000) challenges the idea that researchers monopolise power and authority in research relationships. She contends that within qualitative research paradigms which are more accepting of the subjectivity and standpoint of the researcher, relations of power should be seen as fluid and dynamic and influenced by factors such as age, gender, class and

ethnicity. During the interview, participants can exercise control by declining to answer questions, by introducing new topics, and by choosing when to bring the interview to an end.

Some of these issues came to the fore during my interview with Brian, a senior social worker and one of only two men among my participants. As well as gender, there was another important dimension of difference between us, in terms of class. Though I did not ask any questions about Brian's own background, I did notice that he has a strong Glaswegian accent (I am making an assumption here that having a strong regional accent is more likely to associate someone with a working class background). Listening to my own voice on the tape of the interview, it sounded absurdly prim and middle class by contrast. I felt rather in the position of the female middle class 'softie' who needed to be awoken to the grim facts of 'real life'.

There were not only differences in accent that suggested that Brian and I were positioning ourselves in different places in terms of class and gender. In this interview he used 'swear words' (I can't think of a better term!) and I did not: *'When he was four he was (3) completely fucked up...Seeing some fucking idiot tell me this was the housing department's fault'.*

It is possible that Brian's use of 'swear words' might have been about him 'doing masculinity' and occupying a 'macho' stance and more to do with gender than class positions. All the same, Brian's use of language not usual in official institutional settings packed a powerful emotional punch, which left me feeling 'at a loss for words'. Towards the end of this interview, Brian talked about the impact of the 1989 Children Act.

Extract 5.i: Brian, children and family social worker[3]

1 2 3 4	B:	I mean (.) the Children Act seems to me to have been drawn up by a bunch of (.) very well educated middle class pricks (.) who have no idea of the reality of working with people who (.) perhaps don't read and write very well (.) who (.) who perhaps aren't all that bright

Since I feel that my position in the interview was defined in part by my middle class status, I can't help thinking that in terms of my interactions with Brian, and as a researcher and a woman I was being identified with those well-intentioned but ignorant, well educated pricks!

5.7.3 Ethics and interpretation

The practice of discourse analysis as an interpretative methodology raises even more complex ethical issues. The process of interpretation involves the analyst in imposing patterns and meanings upon participants' talk; taking control of other people's words (Stenner, 1993) to draw conclusions which may be far from participants' own viewpoints. I can only conjecture how participants might wish texts in which they are represented to be interpreted, but I assume that they would resent being presented as either dupes or self-serving. Particularly in examining action orientation of talk, there is a danger that participants can be represented as defensive and preoccupied with maintaining a favourable self-presentation. Whilst participants can be presented as short-sighted and narrow-minded, the analyst can position herself as having the definitive, over-arching vision. Parker and Burman (1993) note the challenge of resisting the temptation to close the text to alternative readings in this way. I have tried to keep open the possibility of different interpretations of my interview data by avoiding the claim that constructions or discourses have 'emerged' from the data, by being tentative in my conclusions and being open about contradictions and inconsistencies in the texts.

[3] A key to transcription symbols used in this message and throughout this thesis can be found at the end of this chapter in Section 5.8.

Harper (2003) has emphasised the importance of a respectful and non-blaming stance towards participants as analysis proceeds. I tried to take at face value the participants' self-presentation as thoughtful, concerned and wishing to help and alleviate suffering. Following Harper's (2003) recommendations, I focused on the talk and its effects, and did not dwell on the 'motivations' of individual speakers, avoiding '*narrowly judgemental or psychological interpretations of behaviour*' (Harper 2003). Moreover, I sited individual accounts in the context of organisational constraints and agendas, avoiding ad hominem interpretations.

One strategy to maximise accountability to participants is for discourse analysts *'to find a way of building into their research opportunities for participants to comment on their own accounts and those of the researcher'* (Burr 1995: 180). However, it is not always possible to make this a profitable exercise. Marks (1993) reflected that researchers' own interpretations tended to be privileged as most valid, thus discrediting stated intentions of 'democratising' the research process. In my own research I sent participants transcripts of their own interviews for them to check for accuracy. None got back to me; either to raise objections or add comments, leading me to conjecture that checking through transcripts was not a priority for these busy practitioners. By the time I came to do the final write-up of the research a number of years had passed since my interviews with some of the participants. Like Harper (2003) I suspected by then the trail would have gone cold, with practitioners having moved on to new jobs or new preoccupations, and trying to trace them to request that they comment on my analyses would be both impractical and outside the expectations I originally placed on participants.

5.8 Key to transcription symbols

(1)	The number in brackets indicates a time gap in seconds.
(.)	A dot enclosed in a bracket indicates a pause in the talk of less than two tenths of a second.
:	Colons indicate that the speaker has stretched the preceding sound or letter. The more colons the greater the extent of the stretching.
( )	Empty parentheses indicate the presence of an unclear fragment on the tape.
(( ))	A description enclosed in a double bracket indicates a non-verbal activity. For example *((coughs)).*
Under	Underlined fragments indicate speaker emphasis.
=	The 'equals' sign indicates contiguous utterances.
[	Square brackets between adjacent lines of concurrent speech indicate the onset of a spate of overlapping talk.

These transcription symbols are described in more detail in Atkinson and Heritage (1984), p.ix-xvi.

Chapter Six: Definitions and Descriptions of Learning Disabilities

6.1 Introduction to Chapter Six

In this chapter, I examine how speakers identify and describe 'learning disabilities' and the 'learning disabled person'. 'Official' and technical definitions of learning disabilities exist in various forms, and are often used to preface academic discussions of the nature of learning disabilities. However, I am not particularly interested in how far participants approximate to these definitions. Instead I examine the process and purpose of definition and categorisation of learning disabilities. This is because I am more interested in is how speakers assemble their constructions of learning disabilities to form what Potter and Wetherell (1987: 138) would call '**interpretative repertoires**'; '*basically a lexicon or register of terms and metaphors drawn upon to characterize and evaluate actions and events'.*

Identifying interpretative repertoires involves looking for recurrent descriptors, metaphors, explanations which have a 'family resemblance' and seem cohere to do some particular kind of discursive work. Edley (2001) described them as the 'building blocks' of conversation, a resource of common sense understandings like books in a public library that speakers can draw on as interactional resources. Thus speakers do not have to construct

interpretative repertoires from scratch; they are available as a cultural artefact to give shape and force to people's arguments.

In this chapter I describe how two key attributes of learning disabilities are discursively employed; intellectual deficiency and social incompetence. These constructs are grounded within narratives where parents with learning disabilities and professionals are described as acting in particular ways and as having particular relationships with 'learning disability'. Whereas the parents are seen as trying to hide the 'truth' of their disability and evade their responsibilities in acknowledging and tackling the resulting 'problems', professionals use their expertise to reveal it.

As cultural artefacts, interpretative repertoires derive their authority from wider discourses and in this chapter I look at how speakers' constructions of learning disabilities link to wider discourses about what constitutes human ability, and what it means to be a person in contemporary social and economic arrangements. As I mentioned in Chapter Four, this process of 'going beyond the text' is avoided by discourse analysts from the discursive psychology tradition (for instance, Edwards and Potter, 1992). However, calling attention to links between interpretative repertoires and wider understandings of personhood suggests ways in which particular discursive resources can establish and maintain themselves by drawing on discourses bolstered by dominant ideologies and power relationships.

Consequently, I link the constructions and narratives to wider discourses relating to the nature of the individual as an autonomous and reflexive human subject, and suggest how aspects of the development of material and social structures have foregrounded and privileged such discourses.

Whilst most of this chapter is taken up what I described in Chapter Four as the first two stages of discourse analysis (namely identifying different ways in

which the discursive object is constructed and locating discursive constructions within wider discourses), I also more briefly consider issues around positionings, and the action orientations and possibilities for practice opened up or closed down by different discourses.

Finally I examine the functions of using these particular discursive resources with relation to the background context of the interviews and the narratives built up by participants, which tend to be concerned with people with learning disabilities failing as parents.

6.2 'Official' definitions of learning disability

> *The entire field of mental retardation is built on the notion of the 'normal' curve and the definition of the other, that is those whose performances either on the intelligence test and/or associated functional measures fall outside the arbitrarily defined Norm [emphasis in original]* (Peter, 2000: 35).

Although terminology, definitions and classifications relating to learning disabilities are constantly debated in academic texts (Luckasson and Reeve, 2001; O'Brien, 2001; Whitaker, 2003), there is some consistency among contemporary 'official' definitions of 'learning disabilities' as a diagnostic term (American Association on Mental Retardation, 1992; World Health Organisation, 1997; British Psychological Society, 2001). These definitions all have in common an assertion that learning disability can be identified by three core criteria, namely:

- *Significant impairment of intellectual functioning*
- *Significant impairment of adaptive functioning*
- *Age of onset before adulthood*

British Psychological Society, 2001: 4

These 'official' definitions share an overarching assumption that learning disability is an (often defining) disorder within an individual comprising a deficit in intelligence and 'adaptive' (meaning skilled and socially useful) behaviour. As Peters (2000) has pointed out above, the abnormality of learning disabilities only makes sense as an aberration from 'normal' functioning, defined statistically with reference to the 'normal distribution curve' in terms of standard deviations from the population mean. This way of defining learning disability fits within a positivist orientation which attests that human and social phenomena can be studied scientifically to establish objective and generalisable truths about reality. Thus characteristics such as 'intelligence' can be measured using a scientific instrument such as the IQ test. The resulting scores would allow an individual's performance to be measured and compared to the performance of others. Those whose performance differs substantially from the majority of the population are identified as abnormal. Therefore as well as performance being measured in quantitative terms, is also judged in value terms as being inferior.

The status of standardised measurements of intelligence has come under fire from many quarters. The social movements of the 1960s and 1970s labelled discriminatory the composition of psychometric tests designed to reflect white and middle class values (Mercer, 1973; Kamin 1974).

Some of the participants do reference 'official' 'scientific' terminology relating to learning disabilities; for instance IQ scores, 'levels' of learning disabilities such as 'mild', 'moderate' and 'severe'. Although quoting specific figures and scores (Pomerantz, 1984) and using technical language is a powerful way of co-opting an expert identity, on the whole, my participants do this rarely, and rather tentatively, as is illustrated in the extracts below:

Extract 6:i: Brian, children and families social worker

1	D:	I mean (.) do you have um (1) what sort of rate do you have of people being
2		referred here (1) um (.) that have (.) identifiable learning disabilities
3	B:	(.) I think we get quite a lot
4	D:	Hmm (.)
5	B:	But I don't think we actually identify them as people learning disabilities (.) it's only
6		if they have got a ( ) involved with them or if the (.) ler learning difficulties are
7		severe (2) I think we've got a lot of people with moderate learning difficulties
8	D:	Right (.)
9	B:	You mean learning difficulties as in people who are identified as having a low IQ
10	D:	(.) well I mean (.) learning disabilities is quite a difficult category to identify (1) I
11		don't know (.) I mean (.) what sort of things would make you think oh this person
12		has got a learning disability?
13	B:	(.) Well (1) I suppose (.) they are identified through the education system
14	D:	Right
15	B:	They had been identified as having a particularly low IQ
16	D:	Hmm
17	B:	Although IQs aren't a particularly good way of measuring things
18	D:	Yeah
19	B:	Generally if it was say eighty (1) ninety
20	D:	Yeah

Extract 6.ii: Catherine, children and families social worker

1	C:	she had been sent to us as having special educational needs (.) but (.) and had
2		been to a special school
3	D:	Hmm
4	C:	But she was always talked about
5	D:	Hmm
6	C:	In case reports (.) that she had mild learning disability.
7	D:	Right (1) so I mean what did that mean to you (.) a mild learning disability?
8	C:	(1) Well (.) it's just that (.) it didn't mean anything does it? ((laughs))

Both Brian and Catherine engage in a process of negotiation around whether their use of terminology will be allowed and accepted. It is worth remembering that I have introduced myself as a clinical psychologist, thus belonging to a profession often identified with the assessment of intelligence, and presumably an expert in such matters. Both participants (who are social workers, and therefore perhaps more likely to distance themselves from 'medical' diagnostic labels) present themselves as sceptical of IQ terms. Brian says (line 17), *'IQs aren't a particularly good way of measuring things'.* He adds later, *'And she had (.) well (.) she was identified as having an IQ of 64'.* In this statement he is careful to distinguish between an IQ score as a

'real' and valid and accurate summary of someone's abilities, and a figure that has been attached to the individual that may be contested.[1] A careful bit of self-correction using a prefacing 'well' and a pause anticipates and heads off a challenge to his use of technical 'IQ talk'. He signals that he is a thoughtful and sophisticated user of potentially powerful terminology.

Catherine distances herself from the use of 'IQ talk' by using the passive voice when describing the label attached to her client, thus indicating that this choice of language should not be attributed to her.

> *She had been sent to us as having special educational needs...she was always talked about...in case reports (.) that she had mild learning disability.*

When I ask her '*what does that mean to you (.) a mild learning disability*', using the language of 'levels' or 'degrees' of learning disability, that suggests that the construct, 'learning disability' can be quantified by means of some objective criterion, Catherine has a couple of false starts and pauses in her response, '*well...it's just that*'. This suggests that she is aware of the conversational principle in interviews that a question should be followed by an informative and relevant answer (Grice, 1974; Molenaar and Smit, 1996). However, she then appears to treat my query as a 'trick question', replying, '*it didn't mean anything did it ((laughs))*', instead of answering the question directly.

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[1] A similar discourse which distinguishes between the IQ score that someone might have been given, and their 'true' abilities can be found in an article part written by a self-advocate with learning disabilities who states here:

> *At the age of thirteen just before I was introduced to facilitated communication, my IQ was tested to be 24. I was sadly assumed to be mentally retarded. No one made the distinction in real life if I was <u>labelled</u> mentally retarded or <u>was</u> mentally retarded* (Rubin et al., 2001: 416, emphasis in original).

Brian and Catherine query the validity of 'scientific' labels and categories. Their stance reflects Jolly's (2003) contention that understandings of impairment have become more ambiguous, including an appreciation that reducing the concept of the person with learning disabilities to an IQ number or diagnosis (Gillman et al., 1997; Peter, 2000) is dehumanising and objectifying. In line with redefinitions of learning disabilities undertaken by the American Association on Mental Retardation (1992) and the World Health Organisation (1997), newer paradigms involved in the definition of learning disabilities attempt to be more sensitive to the positive functional abilities of individuals, their personal history and social context (Burton and Sanderson, 1998; Luckasson and Reeve, 2001; O'Brien, 2001).

6.3 Intellectual deficits of learning disabilities

Despite their reluctance to categorise people with learning disabilities using the technical construct of IQ score, intellectual deficits, of the sort that IQ tests claim to measure are salient descriptors for participants. The short extracts below illustrate how people with learning disabilities are constructed as lacking in cognitive skills, in particular what could be called 'higher order' or more abstract cognitive skills, such as understanding another person's point of view, having a flexible response set, being able to anticipate and predict consequences.

Extract 6.iii: Catherine, children and families social worker

1 2	C:	Well (.) with um this (.) particular woman the basic things were that she couldn't read and write
3	D:	Hmm
4	C:	She had very (.) very poor negotiating skills

Extract 6.iv: Leanne, residential family centre manager

1 2 3	L:	I mean sometimes I think that with people with learning difficulties (.) it depends on the severity of their disability but they actually find it quite difficult to put themselves in the position of a baby.

Extract 6.v: Leanne, residential family centre manager

1	L:	And another area that is a great cause of concern I think is the ability to anticipate
2	D:	Right
3	L:	And that's something that parents with learning disabilities tend not to be very good
4		at

Extract 6.vi: Brian, children and families social worker

1	B:	People who have a (.) functional disability to understand things (1)
2	D:	Difficulties in understanding (.) right
3	B:	Or understanding (2)
4	D:	[So
5	B:	[Consequences of actions, things like that.

The deficits described by participants cued by term 'learning disabilities' are problems with mental processes and learning. Interestingly, the participants accomplish this emphasis through different degrees of particularisation and generalisation. Extract 6.iii, from Catherine's interview follows immediately after Extract 6.ii, at the end of which she refutes the legitimacy of 'mild learning disabilities as a useful diagnostic category (*it didn't mean anything, does it*). She is able to maintain her stance as someone who is sceptical of 'labels', by emphasising the specific attributes of *this particular woman* (line 1). In Extract 6.iv Leanne also manages a possible imputation that she might be employing the category of *people with learning difficulties* in an overinclusive way by adding various 'hedges' to her assertion (*sometimes...I think...it depends*) that parents with learning disabilities find it hard to shift their perspective to considering a baby's point of view. In extracts 6.v and 6.vi the participants are providing generalisations about people with learning disabilities which they put in the present tense, implying permanent and unvarying states; though they are also careful to anticipate possible counter-arguments by use of 'vagueness' (Potter, 1996) markers (*tend to...not very...things like that*).

Thus, participants use a variety of rhetorical devices, either stressing particularity or using descriptions that are vague and global to build sustainable and convincing accounts of people with learning disabilities

having particular fundamental and permanent characteristics relating to cognitive deficits. There is an implied **contrastive** structure to these accounts, with an implication that these deficits are noteworthy because they are not shared by 'normal' people. Whereas people with learning disabilities do not have the ability to 'anticipate' other people's actions or feelings (Extract 6.v), the implication is that the rest of us do. As well as constructing the abnormality of learning disabilities, therefore, the participants are constructing what is normal and expected. As Goodey (1999) has suggested, participants do seem to be able to draw on some readily available understandings of learning disabilities which assume the primacy of mental processing in human endeavour and interaction and also in human development.

> *While it is often admitted that a single generic boundary cannot be drawn for learning disability, a covert unifying theory actually exists: that of incurability, and of the 'mind' and mental development (*Goodey, 1999: 43-44).

People with learning disabilities are viewed as fundamentally and irrevocably lacking in abilities that are viewed as essential for competent operation as an autonomous actor in the social world. Moreover, lacking these cognitive skills means that they cannot be reflexive. Reflexivity could be defined as the ability to stand back and evaluate one's impact on other people and on one's social environment. It is an internal feedback loop which allows the individual and the social world to interact with each other. Davies (1998: 116) asserted that

> *[the] two characteristics, autonomy and reflexivity, are among the most fundamental features of Western conceptions of the individual self (Morris 1994; Taylor, 1986), and such conceptions form the basis of social constructions of personhood. This suggests that one way in which the social category 'learning difficulties' may cohere is that it systematically, albeit implicitly, impeaches the personhood of its members.*

I shall return at the end of the chapter to a discussion of how constructions of learning disabilities challenge the underlying humanity of people with this label and the social and political structures that support our conceptions of what it is to be a person. First I examine how local constructions of learning disabilities work to reinforce the association between learning disabilities and intellectual and social incompetence, summarised neatly by one of my participants:

Extract 6.vii: Pam, clinical psychologist

1 2	P:	I suppose I think learning disabilities implies by its definition that you are socially and intellectually less able

6.4 Hidden nature of learning disabilities

I am interested in the set of descriptions that identify parents with learning disabilities as trying to hide their disabilities, either through covering them up, or through acquiescence, and the consequences that these discourses have for them and for professionals.

Similar narratives were constructed by my participants in which parents with learning disabilities attempt to hide the nature of their disability. In the next two examples, the professionals describe how it dawns on them that they need to revise their initial impressions, and take note of the parents' learning problems, which were not immediately apparent.

Extract 6.viii: Jill, hospital social worker

1 2	J:	She'd gone to school for sort of children with moderate to severe learning difficulties
3	D:	Right
4	J:	Now that was interesting (1) because the ward staff hadn't actually picked up
5	D:	Okay
6	J:	On he:r (1) um (1)
7	D:	[Yeah
8	J:	[But talking to them what (.) what had happened was (.) that she had put the

9		curtains round herself (.) and the staff never saw her
10	D:	Right (1) Okay
11	J:	((laughs)) To keep them all out
12	D:	Huh
13	J:	So you can see how she slipped through the net
14	D:	Yeah
15	J:	Some of them thought that she just couldn't read or write (1) um (.) and (.)
16		[others
17	D:	[hmm
18	J:	Were saying (.) that well (.) um she couldn't say very much about the milk
19	D:	Right
20	J:	Because baby was quite small she was (.) having to record how much milk he'd
21		taken
22	D:	Okay
23	J:	And she wasn't doing it (.) she was (.) scribbling (.) she couldn't say how much
24		milk he'd taken and things like that
25	D:	Right
26	J:	So we had to look at and assess what was going on

Extract 6.ix: Liz, nurse specialist, child protection[2]

1	L:	They certainly would not (.) identify themselves as having learning difficulties (.)
2	D:	Okay
3	L:	They would be the (.) sort of parents that would be very reluctant to admit that
4		they have a literacy problem and can't read perhaps
5	D:	[Hmm
6	L:	[And it's something that you've found out more by chance than anything (.) um
7		(1) and I think that sometimes
8	D:	Yeah
9	L:	Because there are (.) [I don't know
10	D:	[Hmm
11	L:	Because they are perhaps borderline (.) er (.) they have managed to scrape
12		through
13	D:	Right
14	L:	They have managed to get by (.) to the point that they (.) you know (.) er
15	D:	Hmm
16	L:	Had some schooling (.) and then left=
17	D:	=Right
18	L:	And had babies (.) and set themselves up at home (.) and not come to the
19		attention of any authorities
20	D:	[Hmm
21	L:	[Before the birth of their own children (.)
22	D:	((cough))
23	L:	And then it has been identified that there are concerns (.) that they are perhaps
24		(1) [they don't
25	D:	[Yeah
26	L:	Have that much insight into their own learning needs

[2] When she introduced herself, Liz explained that her job title 'Nurse Specialist, Child Protection' meant that she supervises other health visitors on their child protection work.

Liz's use of the generalising 'they' frames this part of her talk as a 'typical' script or scenario. She also references common life events in sequence in such a way as to suggest that this progression is expected and representative of the experiences of mothers with learning disabilities (the mother scrapes through school...has babies...establishes a household...gets in difficulties...comes to the attention of the authorities). Her rhetorical construction also seems to imply an inevitability that not only the mother's incapacity will be discovered by the 'authorities', but also the true nature of her disabilities.

This set of descriptions achieves various outcomes. First it emphasises the pervasiveness of learning disabilities – it is a serious problem that cannot be underestimated, though its true extent may be disguised. In the eugenic literature of the early 20th century, the trope of the 'hidden masses' of feebleminded was common. In the context of a moral panic about feeblemindedness passing into and infecting a healthy population, the supposition that feebleminded men, and particularly women, hid their true natures and passed for normal inspired fear, and justified a range of disciplinary actions from consigning feebleminded women to custodial institutions, to appointing field officers to identify feebleminded people and assess them. In contemporary research, where authors have used statistical means to estimate the 'true' number of people with learning disabilities, they have tended to lament the discrepancy between the number of people with learning disabilities 'known to services' and the mass of unknown cases in the community (Whitaker and Porter, 2002). Valuing People (Department of Health, 2001) has made the creation of a register of people with learning disabilities a goal for local authorities.

Second, these narratives of hidden disabilities highlight the skill of the professional in detecting the learning disabilities, or if they do not do this, it excuses them for overlooking such an obscured phenomenon. Jill achieves

this in Extract 6.viii by using the construction '*some of...others*' (lines 15 and 16) to divide the staff on the ward into two contrasting groups who had each had only a limited, partial view of the mother's 'real' problems. The ward staff, though portrayed as confused, are not held to be directly responsible for their lack of overall understanding. The mother is described as deliberately hiding herself from the staff, by taking the step (and the unusual, even startling nature of this tactic is signalled by Jill's laugh in line 11) of keeping the curtains around her bed closed, thus obstructing the normal process of surveillance and the evaluative gaze of the ward staff. Jill uses the metaphor *she slipped through the net* (line 13) to suggest this mother was 'the one that got away' because in this instance the weave of the net of surveillance and evaluation was too loose. The narrative creates the requirement for Jill (as a social worker and a more autonomous practitioner) to find out what is 'really' going on; '*so we had to look at and assess what was going on*' (line 26).

Thirdly, this construction of learning disabilities as something that the person takes steps to hide links in with the idea that learning disabilities conveys a 'spoiled' and 'toxic' identity that people who 'possess' will at all costs seek to disavow (see Goffman, 1963, and Edgerton, 1967). Todd and Shearn (1997) argue that a learning disability identity is in fact so unacceptable and damaging, that people with learning disabilities are sheltered from the knowledge of their 'true' identity by their parents. Todd and Shearn's interview data suggest that as a consequence, many people with learning disabilities are unaware that they are disabled; they are 'invisible to themselves' (Rapley et al 1998). Liz suggests this is the case when she says that parents with learning disabilities are not only '*reluctant to admit*' (lines 4-5) that they lack essential skills; they also lack '*insight into their own learning needs*' (line 28). Jill describes the mother as naively *scribbling* (line 23) on the record charts to put the ward staff off the scent, presumably unaware that this tactic would make it even more likely that she would be 'found out'.

If parents with learning disabilities refuse to admit their 'learning needs' they cut themselves off from professional support. To avoid this support confirms their limitations in thinking and insight, since professional support is presumed to be good and useful. In this way, these parents make themselves vulnerable to being read as unaware of their own 'real' needs, confirming their deficiencies in thinking and insight.

Extract 6.x: Jill, hospital social worker

1	J:	And she was also into (.) denying that there were any problems but was
2		obviously aware
3	D:	Right
4	J:	And until she was actually able to acknowledge these (.) I don't think that she
5		would have been able to learn
6	D:	Hmm
7	J:	But (.) but whether she would have been able to (.) [I mean (1)
8	D:	[Yeah
9	J:	You can quite understand why someone does that

Jill suggests that this mother (the same one whom she talks about in Extract 6.viii) was at some level 'aware' that she was running into difficulties, but chose to deny them. Here the implication is having 'problems' (here presented as stark facts that are not in dispute) and some awareness of them, places the person in a position of being required to make a public acknowledgement, a confession of not being able to cope. Jill employs the idea prevalent in counselling and self-development literature, that unless one makes a clean breast of one's difficulties, one cannot develop as a person and 'move on'; that some sort of inner, psychological transformation is necessary before further development can take place. Along these lines, Mark Rapley has commented on how use of the concept of 'denial' with reference to people with learning disabilities can mobilise wider discourses of psychotherapy and crime, which position the person doing the denying as evading a moral responsibility to face up to 'the truth', while at the same time actually constructing the 'underlying problem' of the learning disability as a incontrovertible fact that is being avoided.

> *The very use of the term 'denial' accomplishes two linked rhetorical projects: it recruits commonsensical psychologised (or more precisely, psychodynamic) vernacular understandings of people 'being in denial', that is people not wanting to know the awful truth about their cancer or whatever; and simultaneously recruits the discourse of crime, in which 'to deny' a charge is also to acknowledge that a real offence has been committed, while disavowing responsibility for it. Either way, the term cements the 'reality' of that to which people are invited to 'confess'* (Rapley, 2004: 69).

But of course, precisely because the 'fact' of the learning disability carries such negative connotations (analogous to a fatal disease or a crime), the person herself is going to want to draw attention away from it. Thus 'having' a learning disability enters the mother into a conundrum, a Catch 22[3]. Trying to hide such a 'spoiled' identity marks the person out as not only deficient in good sense, but also unreliable and dissembling. However, only a foolish and naïve person would not try to avoid such a label; according to Jill, *You can quite understand why someone does that* (line 9).

6.5 Acquiescence

Stories about parents with learning disabilities being acquiescent, blithely saying yes to everything, occur in different forms in my participants' accounts:

Extract 6.xi: Beatrice, health visitor

1	D:	To start off with
2	B:	Mmm hmm
3	D:	(1) if you could tell me about what sort of (1) what (.) sort of experiences you've
4		had (.) with parents with er (.) learning disabilities
5	B:	Hmm (4) I think on the whole (.) if you are meeting parents for the first time
6	D:	Yeah
7	B:	if this is your initial contact (.) What you tend to find is (.) you're er talking about
8		certain issues

[3] In Joseph Heller's 1961 novel, the eponymous 'Catch 22' was the unsolvable dilemma experienced by fighter pilots during WWII. On the one hand, their missions were so hazardous that only a madman would agree to fly; the only sane thing to do would be to refuse to fly. However, since refusing to fly was a mark of sanity, the pilot refusing could not therefore be mad, and would have to fly.

9	D:	Yeah
10	B:	And they are saying (.) yes to everything
11	D:	Yeah
12	B:	And they're looking at you (.) giving you all the right er (.) nods in all the right
13		places (.) aand you suddenly realise at some stage you suddenly realise (.) well
14		I'm not entirely sure whether this person is taking in all that I'm saying

Extract 6.xii: Catherine, children and families social worker

1	C:	She was one of these people you would talk to and she'd be nodding (.) you
2		know (.) yes yes yes
3	D:	Right
4	C:	And it was only sort of after I'd sort of worked with her for a while and then I'd um
5		(.) see somebody else and um (.) they'd say I was talking to (.)
6	D:	Yuh
7	C:	You know (.)and she said that you said this
8	D:	Right
9	C:	And I'd say (.) no I never said that
10	D:	Yeah
11	C:	And she'd jus:t (.) completely misinterpret [or miss the point
12	D:	[Hmm
13	C:	Or you know (.) hear what she wanted to hear and forget the rest of it (1) so it
14		was quite difficult to work with her

Extract 6.xiii: Claire, health visitor

1	C:	And (1) they did come to clinic for major things that they had to
2	D:	Hmm
3	C:	But they actually wouldn't (1) he (1) they sort of yessed me to death when I saw
4		them on the street because I was bumping into them (.)
5	D:	Hmm: (2) they whatted you (.) sorry?
6	C:	Yessed me to death (1) said yes all the time

This is not the same as actively hiding the learning disability; the naivety and 'simple-mindedness' of this response tactic underlies the person as an incompetent social actor and interlocutor who creates particular difficulties for the professionals working with her. According to Catherine in Extract 6.xii, the person's uncomprehending agreement spreads confusion among professionals (lines 4 – 9). Claire's striking phrase *'yessed to death'* (line 6) conveys her feeling of extreme exasperation. These narratives remind me of research on people with learning disabilities as unreliable respondents, because they operate a response bias – they tend to agree with whatever they are asked (Sigelman et al, 1981; Chong et al,. 2000). Mark Rapley (1995) has examined and critiqued this assumption in his research looking at

'quality of life' interviews with people with learning disabilities and has suggested that the responses of people with learning disabilities show awareness of social rules of conversation and interaction. He has pointed out that, in accordance with conversational conventions, people with learning disabilities are able to pick up subtle interactional cues which indicate that a certain response is expected and desired.

This tactic of acquiescence also makes the person with learning disabilities 'hard to help', as Catherine complains in line 15, because they do not ask for assistance. They do not see their incompetence as something that needs to be addressed.

Why is being acquiescent, being someone, who 'gives all the right nods in the right places' a category marker for learning disabilities? What 'psychological notions of mind' (Goodley and Rapley, 2001) are called forth, which then emerge as syndromes and mental impairments? The assumption seems to be that a 'normal' person would admit that they do not understand, and would ask for clarification. But this notion of normal intelligence seems to overlook other issues that would make it less likely that someone would admit to not understanding, for instance not wanting to seem stupid. Sacks (1984) suggests that participants in conversation strive to bring off 'doing being ordinary', avoiding positioning themselves as different or exceptional.

Another possible interpretation for 'nodding in all the right places' might be not wanting to seem impolite by disagreeing straight out (Kitzinger and Frith, 1999), or feeling compelled to agree because of power differentials between the Health Visitor and the parent and being concerned about appearing contradictory or non-compliant. These possible reasons are closed off by using what Sacks (1992) would call a Membership Categorisation Device of 'intelligence' to distinguish between the categories of 'normal' and 'learning disabled' clients. Choosing different explanations to these 'normalising' ones

positions the person with learning disabilities as 'other' and deficient. It also ignores the possibility that people with learning disabilities are skilled social actors who understand the implications of being uncovered and judged because of their label (Rapley et al, 1998). French (1996: 76) admitted that for her and perhaps other disabled people, denying disabled status may be a survival tactic: *'I am absolutely convinced that the denial of my disability has been fundamental in my success in gaining the type of employment I have'.*

This interpretation is allowed momentarily by Jill as I have already mentioned in my discussion of Extract 6.x above (her comment *'you can quite understand why someone does that'* constructs the mother's denial more as a strategy which is normal and expected). But instead of following it up, Jill reverts to the deficit discourse of someone being too naïve to understand the impact of their actions, and who was unco-operative with professionals who wanted to help her.

Extract 6.xiv: Jill, hospital social worker

1	J:	I mean (.) you can quite understand why someone does that
2	D:	Sure (.) sure=
3	J:	=Very good at covering up (.) literally hiding her difficulties
4	D:	Yeah
5	J:	And something the (.) Women's Aid workers said about her as well (1) she
6		wasn't really prepared to engage with them in learning to do things to help
7		herself ( )
8	D:	Do you think anything could have moved that on or helped her
9	J:	(1) Um (2) time (.) to explain to her that the way she was (.) being was actually
10		going to work against her
11	D:	Hmm
12	J:	She really wanted to have the baby (.) and keep the baby (1) and I suppose it
13		would have taken more time to try and help her understand that pretending was
14		going to lead to her losing the baby (.) [rather than (.) than
15	D:	[yeah
16	J:	Acknowledging and (.) um (.) asking for help might mean (.) learning enough to
17		be able to keep the baby

What are the aspects of the social context that would put the acquiescent individual into the category of 'learning disabilities'? Presumably a 'normal' person would fit in with professionals' view of an acceptable client. The person with learning disabilities who hides their disability or agrees to

anything without real conviction is constructed by needing more time, by Jill and other participants – and professionals repeatedly construct themselves as having insufficient 'time'.

I will discuss how speed and time can be understood as organising concepts in the construction of the individual's place in society in Chapter Eleven, section 11.3. Now I would like to look at how the construction of people with learning disabilities as apt to hide their difficulties can be used, rather surprisingly, to reinforce the authority of the welfare professionals and the psy-complex (Rose 1992) which draws its power from its ability to detect and define deviance.

6.6 The Truth Will Out

There seems to be a dilemma here in constructing what is the 'skilled social actor'. On the one hand, a tendency to dissimulate is a marker for learning disabilities. Hiding one's difficulties is constructed as a deficit in skill and understanding. Moreover, lacking this understanding means that the person will fail what the Booths have called 'the compliance test', namely an ability to assure professionals that they will comply with recommendations. Hiding may be at the level of physically absenting oneself, not being in when the Health Visitor calls, or pulling the curtains around the hospital bed. Acquiescence is also constructed as hiding, pretending that all is well and agreeing to everything, in other words being overcompliant. Again this is constructed as relating to deficits within the individual, rather than a skilful way of diverting professionals.

On the other hand, if learning disabilities can be truly hidden, this creates problems for the wider discourse, and a challenge to the idea that the category of learning disability represents something real, observable and intrinsic to the individual's identity. One way to deal with this problem is to

use a device that Potter and Wetherell (1987) identified in Gilbert and Mulkay's (1984) work with scientists: the Truth Will Out Device (TWOD). Speakers may use this interpretative device to resolve contradictions between discourses (or 'interpretative repertoires'). In Gilbert and Mulkay's work it allowed the scientists to reconcile they different discourses they employed when talking about their work: one an informal, contingent, personality based discourse, and the other a technical, empiricist, academic discourse (Mulkay and Gilbert, 1982).

In the professionals' narratives, despite their attempts to dissemble, the women have been found out and have been identified as disabled and deficient mothers. The true nature of their disability has been grasped, often intuitively by the professionals involved. The following extract continues with Beatrice's interview from the part quoted in extract 6.x1 (page 144).

Extract 6.xv: Beatrice, health visitor

1	B:	What you tend to find is (1).[you're talking
2	D:	[Hmm
3	B:	About certain issues (.) and they are saying yes to everything
4	D:	Yeah
5	B:	And they're looking at you (.) giving you all the right nods in all the right places
6	D:	Hmm
7	B:	And you suddenly realise at some stage (1) you suddenly realise (.) well I'm not
8		entirely sure whether this person is taking in all that I'm saying

Beatrice here highlights the impact of her realisation that the parent she has been working with has learning disabilities, putting the revelation in lines 7 and 8 in first person reported speech for added emphasis and force (Holt, 1996).

In the following extract, Liz privileges the intuition of the health visitor in evaluating the degree of the parent's learning disability, even in the absence of any official diagnosis:

Extract 6.xvi: Liz, nurse specialist in child orotection

1	L:	Often (.) I mean I'm thinking of a couple of families that I've worked with
2		Right
3	D:	And the health visitor's perception (1) the health visitor will identify that these
4	L:	particular families have learning difficulties (.) [that
5	D:	[Hmm
6	L:	The mothers particularly have (.) not diagnosed probably
7	D:	No
8	L:	But in the health visitor' opinion has quite severe learning difficulties

6.7 'Totally Honest'

Earlier, in Section 6.7, I referred to parents with learning disabilities being in an interactional 'Catch 22'. On the one hand parents who hide their difficulties or avoid bringing them out into the open through a tactic of excessive acquiescence are characterised as cognitively naïve and unreflexive. However, given the way that learning disability is so negatively connoted, only someone of limited social and cognitive ability would be foolish enough to draw attention to their own deficiencies. According to the second part of the 'Catch 22', again, the parent is also positioned as an incompetent social actor, but this time, one who is unable to dissimulate. There is an underlying assumption that skilled social interaction involves putting on different roles in different environments, responding to the context to show oneself in the best light.

In the following extract Kelly describes a session where a group of parents with learning disabilities is involved in a role-play about different parenting situations. Kelly suggests that in common with non-disabled parents, members of the group might find that they have competing demands on their time which mean that they focus less on their children. However, the learning disabled parents have not learned to 'fake it', and present themselves in this context as conscientious, involved parents.

Extract 6.xvii: Kelly, family aide worker

1	K:	I think that all parents lose it
2	D:	Hmm
3	K:	And are totally irrational, but that's part of being a parent (.) isn't it
4	D:	Hmm (.)
5	K:	Hunhh (.) because when your buttons are being pushed
6	D:	Hmm
7	K:	And why shouldn't a person with learning disabilities (.)
8	D:	Hmm
9	K:	Also be like that (1) but (.) but when they are doing role-play
10	D:	Hmm
11	K:	They haven't had their buttons pushed (.)
12	D:	Hmm (.) [so
13	K:	[When they come out with this is how you should be (.) whereas I think
14		someone without a learning disability
15	D:	Yeah
16	K:	Would know that well no tha that people think that good parenting is if I (.) get
17		down on your level (.)
18	D:	[Yeah
19	K:	[and play with you
20	D:	Yes (.) yeah
21	K:	But in reality (.) all parents are
22	D:	Right (.) [I'm doing the washing up (.) trying to cook the dinner
23	K:	[like you haven't done your homework, you're watching Home and Away
24		(.) turn it off (.) [do your homework
25	D:	[yes yeah
26	K:	I think that's the reality
27	D:	Yes
28	K:	Whereas (.) a learning disabled parent (.)
29	D:	Hmm
30	K:	(1) um (1) hasn't learned (.) to fake it (.) in certain situations

Here Kelly is rehearsing a 'peformative' theory of social identity, that one takes on a certain social role and enacts the behaviours appropriate to it. In lines 16 and 17 she identifies the expediency of adopting behaviours which are socially sanctioned and approved of when one is being watched and evaluated, such as during a role-play. Kelly makes it clear that she is not criticising the learning disabled parent for being 'irrational' and losing her temper when provoked; the exigencies of everyday family life excuse such behaviour (she and I produce a 'scripted' scenario, in the voice of the harassed mother, in the style of a 'fly-on-the-wall' documentary in lines 22-25). Where the learning disabled parent falls down, and lays herself open to criticism, is in not recognising that while such behaviour might be excused when under pressure in one's own home, a different self-portrayal is required

during a role-play. This might mean 'faking it', doing what is expected, in an insincere way, but recognising that the social consequences of not 'playing the game' are considerable. Though of course, if the parent was to 'fake it' in the role-play situation she would be undermining its whole raison d'etre, which is presumably to be as close to 'real life' as possible, so that professionals can monitor what goes on within the private sphere of the home.

What is required of the parent therefore is a reflexive ability to monitor their own performance in different settings, and regulate the impact that it makes on professional staff who have authority to make decisions in their lives. In the following extract, Rachel, an advocate, makes this fairly explicit, and sees her role in clarifying strategies for practical image-management for parents with learning disabilities.

Extract 6.xviii: Rachel, advocate.

1	R:	it's quite interesting actually (.) just in terms of advocates and how we support
2		people you know (.) one of the things that I hate to say but I think it's quite true is
3		that make sure that your flat's nice and clean and tidy
4	D:	Hmm
5	R:	You've done the washing
6	D:	Hmm
7	R:	You know (.) because people do make judgements (.) the minute they come in if
8		there's something if the place is looking like in a complete tip
9	D:	Hmm
10	R:	(.) that <u>will</u> [affect
11	D:	[Sure
12	R:	that worker's view of that person
13	D:	Hmm
14	R:	Initially and I think that first sort of viewing of someone is really quite crucial a to
15		what then happens (.) what follows

Rachel is not making any claims that there is any intrinsic value in having a flat that is *nice and clean and tidy* (line 3), but suggests that bringing off such accomplishments keeps professional concerns at bay. However, even giving such advice to a parent with learning disabilities may position them as inadequate in making such judgements for themselves. Rachel recognises this and the potential for such advice-giving to clash with the professed role

of an advocate to support a parent in making her own decisions and in getting her views heard, and her recognition is signalled by the disclaimer '*one of the things I hate to say but it's quite true*' (line 3).

Extract 6.xix: Catherine, children and families social worker

1	C:	I mean she was always totally honest at Case Conferences
2	D:	Right (.)
3	C:	That was another thing (.) I believe that if she didn't have a learning disability she
4		would have been a little bit more cunning
5	D:	Hmm
6	C:	You know, she would sit at Case Conferences and say (.) you know the kids
7		make a noise in the morning when I'm asleep (.) so the Child Care Coordinator
8		said (.) well what time do they get up (.) well they get up at about seven (.) what
9		time do you get up (.) oh (.) I don't know (.) about eight thirty (.) nine
10	D:	Huh (.) Right
11	C:	I do get up sometimes early (.) she'd say(.) like this(.) and you'd think(.) four
12		children running around the flat while she's in bed (.) you know (1) um (.)
13	D:	Hmm
14	C:	And she'd just say these things
15	D:	[Yeah
16	C:	[And I think other people would be a little bit more cunning about (1) she never
17		really gave us what we wanted to hear (.) or what we needed to hear.

This suggests a construction of relationships between parents and professionals as being smoothed by the parent's production of what the professional needs to hear. There is an understanding that this might need to be a crafted version of events, and not necessarily an accurate account of exactly what happened.

However, the parent need only be 'a little bit more cunning'. This qualification of 'cunning' is contrasted with the client being 'totally honest'. This is another example of an 'extreme case formulation' (Pomerantz 1986), a rhetorical device that can be employed to different ends. Its use here is to '*defend against or to counter challenges to the legitimacy of complaints, accusations, justifications, and defences*' (Pomerantz, 1986: 219).

Although language users strive to convince that they are honest and reliable, they appreciate that there are many contexts where honesty can seen to be rude (Kintzinger and Frith, 1999) or inexpedient. Though it might not be

legitimate to criticize someone for generally being honest, describing the parent with learning disabilities as 'totally' honest suggests that they are naïve and self-defeating in never adjusting their level of honesty to the expediencies of the situation.

6.8 Thinking and selfhood

This model of the incompetent social actor throws light on how we understand 'normality' with relation to social identity, and the cultural assumptions which underlie our conceptions of selfhood. Whereas Shweder and Bourne (1984: 193) suggest that non-Western cultures '*do not abstract out a concept of the inviolate personality free of social role and social relationship',* there is a tendency in Western societies to distinguish the individual self from the social context. The 'authentic' internal self exists independently from the social roles the individual may enact. It is 'reflexive' in that it is able to self-consciously interpret and evaluate the external social world. By making a distinction between the 'real' self and the personae, or social roles that the self may chose to enact, we create the possibility that we can adopt ways of behaving that do not reflect our true selves. We can present a 'face' to the outside world while our true thoughts and feelings remain hidden.

Bound up with this view of the self, cognitive anthropologist Roy D'Andrade suggests that in the Western folk model of the mind, there is an idea of control of cognitive capacity as a central task of the inner self (D'Andrade, 1987). Like other forms of action, the process of thinking is directed by the self, and through thought the self is assumed to express itself most clearly. Thinking ability also relates to agency and responsibility; if thinking is impaired one cannot be held accountable for one's actions. It is understood that emotions act on this thinking self, but they should not get the upper hand and the thinking self should be able to control its responses to emotions. The

ability to do so is a marker of adulthood; whereas children are impulsive and are swayed by their emotions, adults are assumed to be able to exercise self control.

Moreover, the rise of 'new capitalist' globalized economies in the last few decades further prioritises the abstract thinking and reasoning skills of the reflexive individual, who can adapt to the rapidly changing demands of the post-industrialised labour market (Pitt, 2002)[4]. Sweetman (2003) goes so far as to suggest that reflexivity has become for many of us a habitual mode of relating and responding to the shifting and unstable field of social action not only in terms of employment, but also in relation to leisure, personal relationships and consumption. As Tymchuk et al (2001: xxvi) put it, in considering the future for adults with 'mild cognitive limitations';

> *An increasingly complex, information-based and technologically demanding society presents substantial and growing challenges, particularly in areas relating to reading, arithmetic, processing abstract information and using technology*

Incompetence in these areas is likely to cut the individual off from the labour market, and from employment. The disabled person who does not work represents a burden on society, and is also distanced from employment as an important marker of adulthood and citizenship and the expression of full participation in society (Angrosino, 1998). Even if achieving meaningful employment is a distant fantasy for many people with learning disabilities (Riddell et al, 2001), they are still expected to be moving on the path towards greater autonomy and independence, with assistance from community learning disability services, which in the last thirty years '*have increasingly*

[4] An interviewee in a study of transitions between school and the workplace articulates the changes in patterns and expectations of employment in the following way:

> *You have to have diversity these days if you want to build a successful career. Going back, looking at the changes in the last 20 to 30 years you can't just focus on one career anymore, you really have to be able to do a million and one things these days (Dwyer and Wyn, 2001: 179, quoted in Sweetman, 2003).*

come to stress the importance of the development of social and behavioural competence as a key service goal' (Rapley and Ridgway, 1998: 455).

The foregoing discussion suggests that a culturally dominant discourse of reflexive selfhood forges links between individual identity, cognitive capacity, and adulthood in a model of 'normal' cognitive ability. In this chapter I have shown how participants highlighted deficits in thinking and autonomy in defining learning disabilities and how local discourses of people with learning disabilities as unreflective and unskilled social actors relate to wider discourses of the nature of the self.

6.9 Incompetence as a person and as a parent

So far I have suggested that a number of constructions or interpretative repertoires relating to learning disabilities can be identified in my data, and looked at how these relate to wider discourses of normality and personhood. However, discourse analysis is also about asking questions about why a particular construction might be employed in a local context, in other words the 'action orientation' of the discourse. Burr (1995) reminds us that people construct accounts to achieve various ends, such as offering explanations and excuses, making justifications, or apportioning blame. On the level of the individual speaker, Gergen (1989) suggests that people aim to have their interpretation of events accepted as valid and truthful, and in doing so lay claim to 'speaking rights' or 'voice'.

In order to answer questions about the action orientation of the discourses identified I needed to draw back from the individual accounts and ask myself whether I could see any common narrative patterns (Gergen, 1994) as the participants spoke about their work with parents with learning disabilities. I noticed that in all the interviews the parents referred to had been identified (not always by the participants) as falling short as parents. Participants were

often talking about situations where the parents' care of their children had been judged as so deficient that the children had been removed by the local authority and placed in care. Some children had been permanently adopted into other families. And in many cases the participants had at some level taken part in these processes.

Thus descriptions of these parents as incompetent work towards justifying concerns about their abilities to parent. In Chapter Eight I examine how understandings of what it is to be a parent call into question the suitability of parents with learning disabilities. At this point I suggest that the cultural availability of constructions of people with learning disabilities as impaired persons means that participants can use these ways of talking, these interpretative repertoires to highlight their doubts about whether people with learning disabilities are going to cope as parents, sometimes even before the parent has had much of a chance to actually spend time with her child

Extract 6.xx: Jill, hospital social worker

1	D:	What (.) what sort of (.) what sort of effect do you feel in her case the learning
2		disabilities was having or (.) was likely to have on her way of being a parent
3	J:	Well(.) we talked to other people about her who knew her
4	D:	Right
5	J:	She'd left school the previous year (1) the school social worker faxed me one of
6		the reports and (.) it was talking about her um (1) having a very short temper (.)
7	D:	[Hmm
8	J:	[Getting very agitated very easily(.) not being able to cope with conflict or
9		frustration (.) lashing out, hitting other people
10	D:	Yeah
11	J:	So:o (.) that was a worry (.) thinking that babies are very frustrating (.) how is she
12		going to cope with that (1) so that was worrying
13	D:	Hmm
14	J:	(.) The Woman's Aid workers were saying that she was hopeless with money (.)
15		she can't budget (.) she spends it very quickly(.) she's buying lots of sweet things(.)
16		and not properly looking after herself and um (.) stealing from other people in the
17		refuge
18	D:	Right
19	J:	So that was a worry (.) how was she going to manage to look after herself and the
20		baby (1) and what she had (.) what preparations she'd made for the baby.

In Jill's account, the mother's deficient emotional, social and practical skills are turned into 'worries' about how she was going to cope with looking after

her baby. In fact in this extract Jill does not refer to any of her own observations of how the mother was actually looking after the baby in the present. Past conclusions about the mother's inadequacies are turned into worries about how she will be able to cope in the future.

Chapter Seven: Liberal and Radical Critiques of the Incompetency Construction - 'People First' or 'Targets of Discrimination'

7.1 Introduction to Chapter Seven

In this chapter I look at constructions of learning disabilities which either explicitly or implicitly critique the idea that 'learning disabilities' is a measurable attribute of persons which limits their competences and ability to function as a full member of society, within contemporary discourses of what being fully human entails. I have labelled these critiques 'liberal' and 'radical', rather in line with Celia Kitzinger's stances of 'liberal' and 'radical' lesbianism (Kitzinger, 1987). Whereas a liberal critique adopts the values of liberal democracy which assert our common humanity, and equality before a basically fair and responsible legal system, a radical stance entails a more thorough-going criticism of contemporary institutions as structured to forward the goals and maintain the power of forces which systematically discriminate and exclude those defined as deviant.

7.2 'People First'

I have argued in the previous chapter that constructions of learning disabilities which emphasize deficits and incompetence resonate with wider discourses in such a way as to call into question the individual with learning disabilities' claim to personhood.

By contrast, the 'People First'[1] construction of learning disabilities asserts the underlying humanity and value of the individual. Thus 'learning disabilities' is not seen as an important way of characterising the individual, but as a label which creates and perpetuates stigma, as these quotations illustrate :

> *The Self-Advocacy Movement also points out that every person described as having a learning disability is a 'person first'. People First is the adopted by the international self advocacy movement, whose call is to label jars, not people'* (From NHS National Electronic Library for Health web page 'What is a learning disability?')

> *People look at your disability and not you as a person – that's a common experience.* (Jackie Downer, self advocate, in Goodley, 2000: 80).

Downer suggests that the learning disability label overpowers and obscures any other human qualities and attributes that the individual may possess, a process that is challenged by the 'People First' approach:

> *The fight against the colonisers of learning difficulties...is a fight against the denial of humanity itself: hence this group's insistence on being perceived as people first* Gillman et al. (1997: 690).

This construction of 'People First' has widespread implications for both professionals and people with learning disabilities. It implies that all people have the same rights and responsibilities, and that 'special treatment' or drawing attention to learning disabilities exacerbates the stigma which endangers certain people's participation in society.

[1] I have used the term 'People First' to label a discourse, a way of speaking about people with learning disabilities which I associate with the ideology of liberal humanism, with its emphasis on the core values and attributes that unite people and override differences related to gender, race, or ability. I contrast this to what I argue is a more radical approach, based on the social model of disability. 'People First' is also the name adopted by a network of self-advocy organisations for people with learning disabilities. These organisations often describe the barriers they seek to overcome and their objectives using an analysis and rhetoric linked closely to the social model of disability (see for instance http://www.peoplefirstltd.com/ and http://www.peoplefirstofnorfolk.org/).

Extract 7.i: Leanne, manager of residential family centre

1	L:	On the whole the way we work is no different with parents with learning
2		disabilities
3	D:	Right
4	L:	It's about giving the parents the information that they need and allowing them to
5		make choices

Extract 7.ii: Kate, counselling psychologist

1	D:	I wonder what sort of (.) impact you've felt that having a learning disability has
2		on the way that these women are as parents
3	K:	(2) Um:m (2) I can't say that I place any emphasis on their (.) that they have a
4		learning disability
5	D:	Hmm
6	K:	I just see them as individuals

As a stance, the 'People First' construction is validated by the ideology of liberal humanism which is at the backbone of our legal process. It is also reinforced by the therapeutic discourse of humanistic psychotherapy which Kate references, and which makes self-actualisation the goal of therapy, the coming into being of one's own unique individuality as the ultimate expression of self-development and emotional maturity. This discourse provides a powerful means to 'warrant voice' and justify one's actions through appeals to fairness and equal rights (and who could be against that?).Though none of the participants reference it explicitly, this position is broadly that underpinning 'normalisation' as a philosophy (see section 2.3),

7.3 'People First' and being a client

The 'People First' construction or interpretative repertoire not only asserts the fundamental humanity of people with learning disabilities, it also denies any major differences between these people and others, including those who provide services. The desired relationship between the person with learning disabilities and the professional is equality and partnership. This is the rhetoric which permeates the 'jargon free' publications designed for people with learning disabilities and their carers discussed by Aspis (1999) such as the Open University Study Pack 'Learning Disability: working as equal people.

> *The title of the study pack promotes the idea that equality between disabled people with the learning difficulties label and other groups of people already exists, or at least, is an ideal which can be aimed for* (Aspis, 1999: 176).

One of my participants, Pat, illustrates this point. When I suggested in our discussion that she had found herself taking a directive stance in her work with a parent with learning disabilities Pat spoke of preferring being in a equal contractual relationship with her 'client',

Extract 7.iii Pat, service broker

1 2 3	D: P:	It sounds like you sort of (.) got into the parental role Yes (1) it can be like that instead of being (.) like an equal contract between people on the same level

Chappell (1992: 41) has characterised this approach as fundamentally 'functionalist':

> *The assumption that permeates this argument is that, with normalisation, there is consensus between providers and users. They share the same goals and work in partnership to achieve them.*

If the professional in the 'People First' construction is supposed to be respectful and on an equal footing with the client, what are the expectations for the person with learning disabilities? Based on an understanding of the impact of stigma (Goffman, 1963), Normalisation theory suggests that once 'devalued' people are treated as equal citizens and slotted into valued roles, their behaviour will change. Instead of self-defeating 'handicapping' behaviour which further stigmatises them; such as 'challenging behaviour', or 'deviant' or 'immature' sexual behaviour learned in impoverished environments, they will take on patterns of behaviour valued by mainstream society. Instead of drawing attention to their differences, they should be able to 'pass' as normal in the community. '*The pursuit of equality can be understood as an expression of the celebration of the average which is one – and only one - of normality's central themes* (Jenkins, 1998: 20)'.

This idea that 'People First' constructions are linked to a 'denial of difference' is echoed in statements of self-advocates who seek to distance themselves fro the 'disabled' label altogether: .

> *Would I say I have difficulties learning? No, I learnt well enough, I picked things up very quickly* (Sonya Souza, self-advocate, quoted in Goodley, 2000: 101).

> *Learning disabilities – I don't like that, disability makes you believe that we are in wheelchairs and we can't do anything for ourselves, when we can* (Joyce Kershaw, self-advocate, quoted in Goodley, 2000: 229).

This approach is also articulated by policy-makers, such as Rob Greig, the 'learning disabilities czar' brought in by New Labour to implement the white paper, 'Valuing People' (DoH, 2001):

> *For Greig sees people with learning disabilities as 'citizens' who should have a 'right to a slice of the cake' rather than be regarded as a special case. 'Historically we have tended to say that people with learning disabilities are separate and that is part of the problem'* (Prasad, 2003: 6).

The constructions reviewed in Chapter Six, which conclude that people with learning disabilities, because of their underlying incompetence as people are likely to be lacking as parents, obviously present difficulties for the 'People First' orientation. Participants may want to assert their clients' claims to full citizenship and equality, but how are they going to reconcile this to the process of scrutiny that many parents with learning disabilities they know are undergoing; a process which highlights their deficiencies as parents and turns these into 'worries' about their children? For some of the participants, particularly the health visitors and children and families social workers, this dilemma is even more acute as they see a key aspect of their role as protecting and safeguarding the interests of children.

7.4 Helen's Account

Helen, a health visitor, raised this dilemma when she talked about her work with two parents with learning disabilities, Derek and Frances. Helen

positions herself as professional who is keen to build collaborative and egalitarian relationships with her clients (see Chapter Ten for more detailed discussion about this and other professional positions). She is anxious not to exert overt control over her clients with learning disabilities. She appeared to be particularly conscious of existing discourses that characterise people with learning disabilities as children. When Wolfensberger suggested in 1972 that people with learning disabilities were forced into the role of 'eternal children' by service providers, it was not uncommon to hear them described as 'boys and girls', especially in institutions, or to see people with severe disabilities given children's toys to occupy them. In my experience, most providers of community services do try and offer people with learning disabilities age appropriate support, for instance in terms of dress, language and recreation. However, in more general terms, people with learning disabilities are still denied adult roles, such as that of 'worker', 'employer' or indeed 'parent'.

Extract 7.iv: Helen, Health Visitor

1 2	H:	And I didn't want to be sort of (.) bullying them or battering them (.) that was the difficulty I felt

However, Helen also makes me aware of her professional role of a health visitor, who monitors and safeguards children's' development. When we talk more specifically about the developmental progress of Derek's and Frances' baby, Helen asserts her expert status by using technical terms (e.g.'centile'), and by quantifying the baby's food and growth rate in detail. She uses this expert and professional medical language to refute Derek's claims about the amount his child was eating and to back up her understanding of the baby as not 'doing very well' and at risk of 'failure to thrive'.

Extract 7.v: Helen, health visitor

1	H:	The baby didn't put on weight at all (1) very much at all (.) early on (.) after
2	D:	[So
3	H:	[She was doing all right (.) then she was in hospital (.) and then she never
4		went down (.) above the third centile.
5	D:	Hmm
6	H:	(.) And then she didn't (.) she wasn't doing very well after that (.) and they

7		were saying (.) he was saying she was taking eight once bottles every four
8		hours (.) and keep (.) keeping them down (.) not being sick
9	D:	Right
10	H:	And there's this baby not putting on (.) two ounce a week (.) an ounce and
11		looking thin
12	D:	Hmm
13	H:	And yeah (.) she (.) couldn't have been having that (.) and I think it's
14	D:	Right
15	H:	Because a baby never has that it's (.) not possible (1) um

Helen expresses unease that her role as professional gives her potentially abusive power and carefully forestalls potential criticism that she might have been accused of 'bullying'. She thus alludes to the 'People First' discourse of human rights and partnerships between professionals and disabled people. However, this puts Helen in a quandary. What should she do when, from her perspective as an expert in child development and welfare, she feels that she needs to exert some pressure on these parents to change their behaviour?

Extract 7.vi: Helen, health visitor

1	H:	Yes ((sigh)) I was trying not to be heavy (1)
2	D:	[Hmm
3	H:	[I was trying not to (2) but I could see (.) you know (.)that the child was like (.)
4		late walking
5	D:	Yeah
6	H:	And I could see (.) you know (.) the child's gum disease (.) because the child's
7		gums were all red
8	D:	Right
9	H:	And I said take the baby to the dentist (.) and they said yes but (.) um (.) then
10		they never did it

These extracts suggest that Helen is struggling with the contradictions between the 'People First' discourse and her concerns for the baby's welfare which she implies are related to the parents' neglect and dismissal of her advice. She describes situations where she has been unable to be prescriptive or to enforce her suggestions because of *'trying not to be heavy'*.

7.5 Social deprivation hypothesis

I suggest that participants attempt to solve this discursive dilemma by repositioning the parents with learning disabilities as 'the same as' particular others, namely members of deviant and devalued groups; those experiencing poverty, social deprivation, those who have been abused or institutionalised. Their limitations are therefore seen to be the result of limited and deprived life experiences.

Extract 7.vi: Kate, counselling psychologist

1	K:	But I mean she (.) she does have a very mild learning disability
2	D:	Okay
3	K:	And there are there other issues that are lot more important to her ability to parent
4	D:	What (1) what sort of things?
5	K:	Her family background
6	D:	Right
7	K:	Just (.) [horrendous
8	D:	[Hmm
9	K:	And I have to say (.) other people that are referred to me have a background that is
10		more important than the learning disability
11	D:	Right
12	K:	(1) I don't know (.) perhaps it's the area that I work in (.) in [W Borough]

Extract 7.vi Pam, clinical psychologist

1	D:	Do you (1) you said that you do have contact with some clients who do have
2		parents who do seem to have learning disability (.)
3	P:	Hmm
4	D:	What do think has been the impact on their lives (.) the lives of the children
5	P:	It's really hard anyway (.) because it does get so muddled up with deprivation
6	D:	Right
7	P:	If you're unemployed (.) or you don't have good help (.) and live in areas of
8		crime and get victimised by your neighbours (1) it's quite hard to disentangle
9		(1) what causes what (1)
10	D:	[Yeah
11	P:	[There are multiple problems (.) but they are the people who I see and who
12		get referred to Psychology (1) they are not usually the people without a care
13		in the world

These accounts emphasise the importance of the individual's social context; the family, the neighbourhood and the locality, as explanations for the personal deficiencies. This analysis runs counter to a recurrent theme in the advocacy orientated literature about parents with learning disabilities – that professionals attribute any difficulties to the parents' skills deficits, and ignore contributing social factors, such as poverty, stigma, trauma, lack of community resources (Booth and Booth, 1996).

Kate and Pam use 'short hand' words to conjure up images of social deprivation. Kate simply invokes the name of the inner city borough where she works, Pam mentions *'areas of crime'* (line 7). As a listener I am left to fill in the blanks with pictures of poverty, careless parents, out of control children, bullying neighbours. These are assumed to be inevitable correlates of poor, inner city environments and the determinants of sub-standard parenting. Under these circumstances the impact of the individual's 'learning disabilities' is overshadowed by the impact of social deprivation. This account thus sidesteps an account of learning disabilities as based on organic impairment. There is no essentialist difference between the person with learning disabilities and other people equally caught up in the localised 'cycle of deprivation'.

On one level these explanations might be seen as attempts to avoid individualising deficiencies in parenting and to resist blaming the person with learning disabilities themselves. On the other hand, this account does not take into account more complex factors such as family resources, ethnicity, gender, physical environment; factors which may predispose families towards vulnerability or resilience in the face of 'social deprivation' (Jack and Gill, 2003).

The social deprivation account of learning disabilities in the past has led to optimistic, broad-based 'social engineering' schemes for the prevention of underachievement. One large scale project, beginning in 1965, is HeadStart in the USA, which over the following four decades has allocated extra resources to enhance the physical, emotional and psychological development of low-income children at risk of educational failure.

> *The belief at the time was that familial mental retardation was largely the consequence of economic deprivation, and, therefore, the only enduring solution to the problem was to mount a broad-based attack on the root causes of poverty, lack of education and discrimination. According to this theory, individuals with mild mental retardation would benefit from the rising tide of improvements in generic health care, housing, job training,*

employment, and public assistance programmes (Gettings 2001: 43).

Perhaps we no longer imagine that we are living in an era of a 'rising tide of improvements' in welfare provision. Years of economic uncertainty and government rhetoric geared to undermining our expectations that the state will undertake the difficult job of fair and equitable redistribution of resources may be behind the tone of fatalism which can be detected in some of my participants' discussions of the scale and impact of social deprivation.

Extract 7.vii: Brian, children and families social worker

1	D:	Right (.) I mean (.) how (.) how do you see the future for her
2	B:	(.) For her?
3	D:	Yeah (.) um: (.) how would you like to see it (.) if you like
4	B:	(3) ((sigh)) Well (.) I don't think (1) I mean she's kind of doomed
5	D:	Hmm
6	B:	I think some people are doomed the minute the sperms hit the egg
7	D:	Huh
8	B:	(.) I know that sounds totally fatalistic
9	D:	[Well
10	B:	[No (.) but she was born into a totally dysfunctional family

Brian constructs the client from a 'totally dysfunctional family' as doomed to further failure and deprivation, effectively not having a 'future' at all. As was rather typical in this interview, Brian adopts a rather emphatic style, using 'shock tactics' and overstatement to make his point. His position throughout was 'streetwise', aware of the harsh realities of the situation, in the face of my slightly embarrassed middle class dithering and mild protests (line 9).

7.6 'Targets of Discrimination'

I turn now to another interpretative repertoire or set of constructions that professionals offer relating to parents with learning disabilities. Instead of seeing the 'problem' of learning disability' as something residing within the person, the 'problem' is located in the social context which discriminates against the disabled individual by erecting barriers which prevent their full

participation in society. Unlike the 'People First' repertoire, the focus is not on the individual at all, but on the social response to people with particular characteristics. Participants who use this construction do not minimise or explain away the person' impairment's or limitations, they do not claim that the person is the 'same as everyone else'. However, they are critical of the social response to these impairments, which denies the parent with learning disabilities the sort of helpful, supportive response which would mean that they were able to manage better as a parent.

Extract 7.viii: Carol, advocate

1	D:	What do you think the impact of having a learning disability is on these parents
2		(.) I mean (.) maybe talking about the younger mother who you sort of
3		described earlier (.) what do you think that that the impact that that's had on her
4		(.) and how she's managed to be a parent
5	C:	Um (1) I don't know (.) and I'm not sure that it's a particularly fair question
6	D:	Hmm
7	C:	In that she has a learning disability (.) always has and nothing else was going
8		to be
9	D:	Hmm
10	C:	She is who she is
11	D:	Hmm
12	C:	And part of who she is is her learning disability
13	D:	Hmm
14	C:	Um (2) I think (.) the question really is what (.) impact should the services
15		around her have on her as a prospective mother
16	D:	Hmm
17	C:	And what should services and the wider community do to support her in her
18		possible parenting role
19	D:	Hmm
20	C:	Knowing that she's going to find it hard

In this part of the interview, Carol takes a very firm stance and goes as far as violating one of the conventions of the interview as a particular genre of interaction, namely that the interviewee is obliged to answer the questions that the interviewer poses (Molenaar and Smit 1996). By criticising the 'fairness' of my question Carol suggests that I am making an underlying assumption that because having learning disabilities has a negative effect on how people manage in their lives, the onus is on the person with learning disabilities to act more 'normally'. Carol's view is that the onus is on '*services and the wider community*' (line 17) to offer the support which would help her client manage as a parent.

Carol does not deny the 'difference' of the mother with learning disabilities. She says '*part of who she is is her learning disability*' (line 12). However, she does not feel that discussion of the person's learning disabilities should be the key issue in the debate about parents with learning disabilities. Rachel, another advocate for people with learning disabilities makes as similar point.

Extract 7.ix: Rachel, advocate

1	R:	(1) I think one of the biggest impact is not actually the person (.) the parent
2		with the learning disability
3	D:	Yes
4	R:	It's the fact that services (.)
5	D:	[Yes
6	R:	[discriminate against parents with learning disability

Extract 7.x: Rachel, advocate

1	R:	It's not an equal playing field (.) they don't get a fair chance
2	D:	Hmm
3	R:	They don't get
4	D:	Hmm
5	R:	The right services (.) and so therefore that does have an impact on their ability
6		to parent

Rachel's use of words like *discriminate* (line 6), *equal* (line 7) and *fair* (line7), locates this construction of people with learning disabilities within the social justice agenda, with its links to ant-discriminatory, 'rights' movements, such as movements for black and women's rights, and particularly the disability rights movement, with its roots in the social model of disability.

Other respondents who do not so explicitly associate themselves with a disability rights perspective, nevertheless draw attention to the discrimination and exclusion faced by parents with learning disabilities.

Extract 7.xi: Sue, health visitor

1	S:	She's been (.) sort of (.) I suppose hurt at other mother and baby groups and
2		mother and toddler groups (.) and therefore is (.) I suppose reluctant to use
3		those services again now...
4	D:	And it sounds like it has been difficult for her to get much out of going to
5		normal groups
6	S:	That's right (1) because she's turned round to me and (.) said (.) you know(.)
7		people are making fun of me and laughing at me (.) and I didn't like that

Sue's lively and engaging account is animated by direct quotation (line 7) in order to mobilise sympathy for the mother she is describing. However, whereas Sue is talking about other mothers and members of the local community as being bullying and rejecting of the mother with learning disabilities, Rachel and Carol talk about 'services' as being discriminatory. Their discourse is more depersonalised, and the focus of their critique is the institutionalised barriers faced by parents with learning disabilities.

Rachel and Carol structure their arguments along the lines of the Social Model of disability which I have described in detail in the literature review in Chapter Three (see Section 3.4). This approach challenges the assumption that cognitive or physical impairments necessary lead to experiences of social restriction or social exclusion and sees disability as a form of social disadvantage created by discriminatory and intolerant economic and social arrangements. These arrangements combine to put about barriers against the full participation of disabled people who are viewed as socially and economically redundant.

7.7 Liberal and radical ideologies

In this section I shall further discuss the 'People First' and 'Targets of Discrimination' discourse, identifying them with 'liberal humanist' and 'socially radical' ideologies respectively. I go on to summarise the opportunities for action suggested by these discourses.

Liberal humanism, with its roots in the Enlightenment, and its imprint on many of our current institutions and social arrangements, can be said to be a 'heavily legitimated' (Burr, 1995) standpoint in contemporary society.

> *Liberalism...is the specific set of ideas, developed with the bourgeois revolution, asserting the importance and autonomy of the individual as a discrete unit possessing certain rights independent of the state and anterior to its very existence* (Kitzinger, 1987: 35).

This approach, based on the separation between the 'public' and 'private' domains, emphasises the uniqueness and ungeneralisability of individual experience, while claiming our equal rights to happiness and self-fulfilment. The 'People First' discourse discussed above has a distinctly liberal humanist flavour in its highlighting of the irreducible, underlying humanity of people with learning disabilities, as well as its suspicion of the 'label' of learning disabilities as a form of 'stereotyping' which obscures the uniqueness of each individual. However, I have already pointed out the way that this discourse of disability can obscure potentially oppressive power imbalances between people with learning disabilities and the professionals who support them. Moreover, my participants suggest that the 'People First' discourse relies on the person with learning disabilities showing that they can be a certain kind of individual. The ideal individual at the heart of liberal humanist ideology has little need of state intervention. They are self-reliant, responsible, ordered and self-regulating. When people with learning disabilities are judged to fail to meet these standards, they are assigned an inferior status of personhood, along with society's unfortunates, the poor, the feckless and the socially deviant.

By contrast, seeing parents with learning disabilities as 'Targets of Discrimination' focuses on the biased and regulatory nature of social institutions, which are organised in such a way as to exclude disabled people. Thus, the social model of disability, along the same lines as radical feminist lesbianism (Kitzinger, 1987) entails a rejection of personalized and individualized interpretations of what constitutes disability or lesbianism. Just as heterosexuality from a radical lesbian perspective is described as a socially constructed and institutionalized structure which is instrumental in the perpetuation of male supremacy, so

disability is understood as the experience of being systematically disadvantaged through socially constructed barriers which reinforce taken-for-granted assumptions about what is 'normal' and acceptable in appearance, physical ability and cognitive achievement.

As mentioned above, the social model of disability draws attention to the importance of political organisation and protest for people with learning disabilities and their supporters. The target for intervention is to achieve legislative change and the transformation of our social institutions. In the review of literature chapter I have discussed how this model has not always delivered hoped-for outcomes for people with learning disabilities. In the next section I shall look at how professionals reflect on their experience of using and operating within this discourse.

7.8 Defeated or defiant?

Three out of the four speakers quoted in this section are professional advocates for people with learning disabilities who support people with learning disabilities to get their message across, especially when they are being ignored and dismissed by social institutions. Many advocates therefore see their role explicitly as criticising and pressing for change of social institutions. Here three advocates reflect on the impact of their work:

Extract 7.xii: John, advocate

1	J:	Sorry but I'm feeling disillusioned as an advocate here
2	D:	Yes
3	J:	I just came away you know I had long discussions and to get a sense was
4		there anything else I could do (.) you know
5	D:	Hmm
6	J:	Was I missing something here or is it just that difficult
7	D:	Hmm
8	J:	And it's just that difficult (.)

Extract 7.xiii: Carol, advocate

1	C:	We we do advocacy for people with this client group and people with this
2		client group get pregnant
3	D:	Hmm
4	C:	And have a right to have families
5	D:	Hmm
6	C:	And unfortunately always seem to have to battle to have them
7	D:	Hmm
8	C:	And that's a fact that is
9	D:	Hmm
10	C:	And I'd love to change it (.) but (.) I'm not sure that I will ever achieve that

Extract 7.xiv: Rachel, advocate

1	D:	Have you seen any changes over the (1) the last couple of years (.) that
2		you've been in post
3	R:	No=
4	D:	=no (.)
5	R:	It's very disheartening (.)

My first reading of these utterances left me also feeling 'disheartened' and discouraged. It seemed that a radical and liberatory discourse with an explicitly activist agenda was leading to a dead end of defeat and disillusionment. We might conclude that the speakers are telling a story about the way that a discourse that challenges the status quo is marginalised, so that those who employ it are disempowered and thwarted. These accounts can be read on one level as speakers attempting to communicate internal states of feelings of frustration and despondency. However, discourse analysis orientates us away from reading these utterances as simply 'reflections' of speakers' inner world of feelings and beliefs. We are led to consider what these speakers might be trying to achieve through the language they use, in terms of their own self-presentation, and their political and moral stance.

As discourse users, these speakers are engaged in what Gergen (1989) has called 'warranting voice'. They are making claims for their right to be heard and taken notice of. They present versions of themselves which make what they say come across as valid and legitimate. Gergen suggested that in our culture one very effective way of 'warranting voice' is to refer to mental events, or characteristics of mind as form of legitimation. As examples, Gergen referred to different mental processes such as

observation ('I saw it with my own eyes'), rationality ('My position is based on reason and logic') and moral engagement as justifications for voice, and ways of challenging counter-moves by other discourse users.

From this perspective using terms like '*disillusioned*' as John puts it (line 1) or '*disheartening*' (Rachel, line 5), may be seen as attempts to warrant voice. After all, to have 'illusions' is to be naïve, inexperienced and deluded. The warranting claim these speakers are proposing, as Gergen suggests, is bolstered by a reference to a mental ability, the ability to adopt a sharp-eyed, realistic understanding of complex and challenging truths in an unjust world. Their position is along the lines of 'while others' understanding is clouded by wishful thinking, I see clearly the bitter reality of an inequitable system.' Their language asserts the truth of their vision with compelling finality: *'It's just that difficult...That's a fact that is'.*

This presentation enhances the credibility and stature of these participants, and fends off possible criticism that their social model critique of existing social institutions is idealistic and unrealistic. In fact, these speakers construct existing unjust social institutions as obdurate and resistant to change. However, this construction can itself be seen as a form of challenge to a liberal humanist view of human progress which would suggests that knowledge is divorced from power, and that advances in knowledge will be in the best interests of all. This historicist view would claim that as social institutions become better informed about disabled people's lives they will be increasingly 'enlightened' and progressive in their practices. A discourse which emphasises the entrenched and institutionalised nature of discrimination against disabled people can itself be seen as a discourse of resistance.

Extract 7.xv: Pam, Clinical Psychologist

1	P:	I do get outraged about how things are (1) I got outraged last week (.)
2	D:	[Yeah
3	P:	[It just seems(.) talking to some people from the national People First(.) and
4		the things that they can't change about their lives and (.) all this about choice
5		and having person-centred planning
6	D:	Hmm

7 8	P:	They are perfectly articulate (.) able assertive people with learning disabilities who can't change basic aspects of their lives
9	D:	Yeah
10	P:	And that's outrageous.

Pam contrasts the service rhetoric of '*choice and...person-centred planning'* with the inflexibility of social structures which prevent people with learning disabilities from real decision making. She further justifies her anger and frustration by portraying the people with learning disabilities in her example as having status, representing a national organisation ('*from the national People First*') and having a high level of competence ('*they are perfectly articulate (.) able assertive people with learning disabilities'*).

This discourse draws attention to the operation of power in regulating and oppressing deviant groups, in a way that undermines the authority of the discriminating institutions: '*Power is tolerable only on condition that it mask a substantial part of itself. Its success is proportional to its ability to hide its own mechanisms'* (Foucault, 1976: 86).

What was once taken for granted as constituent of the 'normal' and inevitable arrangement of social relations comes to be characterised as unacceptable, and as Pam puts it 'outrageous':

Chapter Eight: Children and Parents

8.1 Introduction to Chapter Eight

The paradox of family life is that although the family is the site of our most intensely private longings, desires and relationships, it is also the site of intense scrutiny and regulation by the state. In this chapter I examine how this paradox is played out from the perspectives of professionals who are reflecting on multiple relationships; parents with learning disabilities and their children; professionals and parents; professionals and children. I examine constructions of parenting, of children and of professional responsibilities vis-a-vis family life. These constructions relate to wider discourses which underlie relationships between adults and children in our culture, involving the privatisation of responsibility within the family and the focus within family life on facilitating children's development towards adult skills and status. Finally I return to the tensions and contradictions involved in state intervention in family life and reflect on how professionals construct them and attempt to resolve them.

8.2 Parents and children: relationships of responsibility and care

Extract 8.i Pam, clinical psychologist

1	P:	Maybe I have a rather (1) grandiose notion of what a parent should be like (1)
2	D:	Hmm
3	P:	But um (.) yeah (2) I suppose (.) I mean I'd like to think that they would
4		understand their schoolwork and social situations
5	D:	Right
6	P:	And you know (.) be able to pay the bills (.) generally be able to take
7		responsibility and (.) um and know more than the children did

Extract 8.ii Liz, nurse specialist, child protection

1 2 3	L:	Trying to again encourage the parents to undertake more responsibility for the children (.) be aware of the children's needs (1) they've got too high expectations of the child's needs for example

'Taking responsibility' can have different facets. Pam seems to be suggesting that the parent is the one who mediates between the child and the complex outside world, protecting the child from the confusion and anxiety of understanding and dealing with the adult realm of tricky social situations and money worries. Liz emphasises her expectation that 'taking responsibility' means that the parent will understand and take care of 'children's needs'. Moreover, Liz sees it as part of the health visitor's role to foster a sense of responsibility in parents. Mayall (1990) has suggested that child care professionals often operate under a general assumption that many kinds of parents, not just parents with learning disabilities, try to evade taking responsibility, and the health professional has to counter this:

> doctors and nurses and others commonly note, as a truism, that many parents are irresponsible and that it is one of the tasks of professionals (from their higher moral standpoint) to teach them responsibility *(Mayall 1990: 208).*

One important aspect of 'taking responsibility' as a parent that Pam mentions is to 'know more than the children did' and to maintain the demarcation between the parent who is more able and more skilled and the child who is still in the process of learning and developing. Predominant 'deficit' discourses of people with learning disabilities which have been explored in previous chapters characterise these individuals as lacking thinking ability. They are people who don't know much. What happens when they have children who do not themselves have learning disabilities? What happens when the children know more than and intellectually 'overtake' their disabled parent? Rachel argues that this is going to raise questions about the suitability of the parent with learning disabilities to care properly for a child:

Extract 8.iii Rachel, advocate

1 2 3	R:	(.) I know one of the biggest questions that seems to be asked is what happens when (1) I don't like getting stuck on IQ's I'm not sure it's particularly helpful
4	D:	Hmm
5	R:	But you know when the child is potentially
6	D:	Hmm
7	R:	Functioning at a higher level than the parent

In other parts of her interview, Rachel, as an advocacy worker for parents with learning disabilities,, resists the 'learning disabilities as deficit' discourse. Here she offers a disclaimer about finding talk about IQ measurement reductionist and unhelpful. However, she uses a framework which assumes IQ is an indicator of 'higher functioning'. In the context of the issue she is introducing, the in adequacies of the parent with learning disabilities' inadequacies are back in the spotlight, and what follows is a particular construction of the child that these deficits call forth.

8.3 Carefree childhoods

Extract 8.iv Helen, health visitor

1 2	H:	And I mean (.) I've witnessed arguments between the two of them and um (.) it was very difficult to see who was the child and who was the parent

Extract 8.v Helen, health visitor

1 2	H:	I mean it was very difficult to see who was the child in the relationship to be honest
3	D:	Right
4 5	H:	The mum (.) the (.) the ten year old was doing things like (.) getting all the kids up (1) hmm (.) making them breakfast
6	D:	Yeah
7	H:	Um (.) you know (.) I mean changing nappies (.) doing a lot of housework

Research on parents with learning disabilities reflects a similar concern that families where the children are more able are 'unbalanced' and pathogenic. O'Neill (1985) coined the term 'Huck Finn Syndrome' to explain the risks that brighter children face in a family where a parent has learning disabilities. Naming this phenomenon a 'syndrome' confers a medical authority and sense of inevitability to the process of pathologizing children with learning disabled parents.

Extract 8.vi Sally, family centre manager

1	S:	Carla is extre:mely bright (.) extremely precocious
2	D:	Hmm
3	S:	Wonderful child (.) but she'll run rings around her parent (.) but the only
4		thing about that is then (.) obviously (1) Carla's got the burden of looking
5		after her mother (1)
6	D:	Right
7	S:	You know (.) because in a few years time (1) the (.) you know (.) the
8		concern is that she's going to outgrow her mother
9	D:	Right
10	S:	And (1) and who's going to be looking after her
11	D:	Hmm
12	S:	It's quite (.) a (.) lot (.) it's: quite a burden (1) for a young child to take on

The concerns of these participants about disruptions to the 'natural order' of things if the child has abilities that the parent lacks, has resonances with the 'young carers' debate of the 1990s (Olsen, 2000). 'Young carers' - children who assume caring responsibilities for disabled parents - emerged into public consciousness as a social issue in the 1990s in academic research (Aldridge and Becker, 1993), media concern and public policy. Eventually young carers were included within the Carers (Recognition and Services) Act of 1995, making them eligible for a Carers Assessment and placing a responsibility on local authorities to consider their requirements alongside the person they were caring for (Deardon and Becker, 1998). There has also been a growth in dedicated 'young carer' services, mainly delivered through voluntary sector agencies such as Barnardo's and YMCA (Underdown, 2002).

Keith and Morris (1996: 92) noted that a recurring theme of the 'young carers' literature is a preoccupation of the topsy-turvy nature of adult-child relationships in household where a parent is disabled:

> *Using the words 'young carers' therefore assumes that we are talking about a situation where a child or young person is taking responsibility for an adult, usually their parent – and that a reversal of roles is therefore involved, with the child 'parenting' the adult.*

We have seen this construction of role-reversal in my own research participants' talk. It is a dominant image, particularly in the media, and suggests a deep unease with the idea of children stepping outside their normal role of care receivers to give care themselves. The caring role is

assumed not only to be 'unnatural' for children, but also to have a negative impact on them. Even the titles of some of these publications – 'Punishing children for caring' (Aldridge and Becker, 1993) or 'I'm growing up too fast' (Underdown, 2002) underline the argument that caring disrupts and blights 'normal' childhood and places onerous restrictions on children's access to social, educational and employment opportunities. The conclusion drawn is therefore that the parent's disability places young carers in the position of 'victims' (Olsen, 1996), who are cruelly robbed of their childhoods.

Extract 8.vii Catherine, Children and Families Social Worker

1	C:	She was a very bright child actually
2	D:	[Right
3	C:	[Very bright (.) um (1) but (.) [um]
4	D:	[Hmm]
5	C:	She just didn't know how to relax (.) how to play
6	D:	Yeah
7	C:	How to be a child (.) that's something that she just hadn't had (1) so (2) but
8		how that will effect her when she's older I don't know

Catherine refers to a construction of childhood which requires the child to be carefree, inhabiting a realm unmarked by worries or responsibilities, where. the defining activity is not caring 'work', but play. This does not mean that play is not a serious matter. The 'job' of the child is to play. Other writers have remarked on the central status of play in developmental and pedagogical discourses (Brooker, 2002). Play is seen as the main vehicle of learning in early childhood and acquiring vital cognitive, social and personal skills. Catherine hints at the longer term implications of not 'doing childhood' properly and not playing (line 8).

Extract 8.viii From interview with Claire, health visitor

1	D:	I mean (.) um (.) how do you feel about the relationship between Carla and her
2		daughter
3	C:	(3) I'm not sure (1) I'm not sure how much respect the little girl has for her
4		mother (1)
5	D:	You (.) sort of hinted at that before a bit (.) that um that was a worry
6	C:	Yes=
7	D:	= That the daughter was sort of brighter and the effect that had
8	C:	Yes
9	D:	Hmm
10	C:	And she: (1) er (.) and the little girl does tend to listen a lot to adult
11		conversations
12	D:	What (.) she listens when she's being talked about

13	C:	Mmn (.) oh yes (1) I noticed that last visit in fact
14	D:	Hmm
15	C:	I mean I stopped (1) the previous visit she'd been at nursery
16	D:	Right
17	C:	The last couple of visits I'd wanted to see the daughter as well as the
18		grandmother and the little girl has been there as well because it's summer
19		holidays
20	D:	Yeah
21	C:	And rather than going off and playing like a lot of them do after a little while (.)
22		she's just there ((laughs))
23	D:	Huh
24	C:	You know hanging out (.) not even (.) you know (1) [just there listening
25	D:	[yeah
26	C:	And I don't think it's a good idea

Claire expresses her discomfort at the presence of a child witnessing adult affairs. Like Catherine, it strikes her as 'unnatural' that the child does not go off and play, that she is interested in adult conversations. This child raises concerns because she is in the wrong sphere, in the adult sphere where decisions are made, rather than the child's sphere, out of the main picture, playing off somewhere, enjoying the carefree fun of the summer holidays. This child is knowing and precocious and lacks respect (line 3) for her mother. There is a hint that this child who lacks respect is going to be hard to control. The child is *deprived* of normal childhood pleasures, but also potentially *depraved* (Hendrick, 2003) by her knowledge of the adult world.

This construction also makes negative inferences about the disabled parent. What sort of parent would subject a child to such a cruel fate? Presumably one who is selfish and neglectful (Olsen 1996) or at the very least, ignorant and thoughtless.

However, this discourse of deprived 'young carers' has met with forceful criticism from sociologists of disability. Keith and Morris (1996), as disabled feminists and mothers themselves, have resisted the implication that there is commonly a 'role reversal' between a disabled parent and 'young carer' child, and have deconstructed terms 'caring' and 'carer'. They maintained that there is a conflation in the use of the term 'caring' between taking responsibility for someone, and providing help with personal care tasks. Receiving help with personal care does not mean

that a disabled person should lose their autonomy and control over how such help is provided (Morris, 1993). Whereas children may contributing in practical and physical ways to their parent's care and the maintenance of family life, the disabled parent does not relinquish the core task of parenting, *'the concern and sense of responsibility that parents have for their children's welfare in all its manifestations'* (Keith and Morris, 1996: 94).

In this formulation, parenting is defined as feelings ('concern') and control ('responsibility'). In fact, Keith and Morris have most to say about the latter. In line with other theorists from a social model of disability perspective (Olsen, 1996; Olsen and Parker, 1999) they have asserted that services should address the powerlessness, disadvantage and restrictions experienced by disabled parents, including lack of access to appropriate support. Lack of such support means that children (like other 'informal' unpaid carers) have to step into the breech:

> *Within this frame, the 'problem' of young carers and children affected by disability is a by-product of the inequality experienced by disabled people and therefore must be tackled by addressing the needs of the disabled family member (Banks et al.,2001: 810)*

Services are therefore seen to have a role in bolstering up the position of the disabled parent in directing family affairs, so that children are released from the 'burden' of caring:

> *We believe that in the vast majority of cases, the parent is both willing and capable of making decisions about the organisation of the family. Where appropriate services are provided for the family member who needs assistance, it is much more likely that the child or young adult can get on with the ordinary business of growing up* (Keith and Morris, 1996: 97).

Although they have started from a position of critiquing the 'young carers' literature, Keith and Morris (1996) seem to share the supposition that children deserve a childhood that is carefree and without responsibilities, and that to expect children to take on caring work is to exploit them and restrict the scope of their lives. According to this formulation it is important

to preserve the asymmetrical relationships, not only of care, but also of power between parents and children. In common with the 'young carers' literature, there is an assumption that in comparison to 'normal' families, 'young carers' are unusual in undertaking care work within the family, as if these children are uniquely disadvantaged in having to assume responsibilities within family life (Olsen, 1996).

8.4 Responsible children

In fact, 'taking care' of others many well be a normal part of childhood, though one so seldom remarked on to be almost invisible. In this country, this may be particularly the case in ethnic minority families. Brooker (2000) asked Bangladeshi mothers of children about to enter Reception class whether the children had any responsibilities at home and was told that (of course), the children were too young. However, Brooker herself noted that a number of children looked after younger siblings, and participated in domestic chores and food preparation, often with a remarkable degree of skill and confidence.[1]

Booth and Booth (1998) take issue directly with what they call 'the myth of the upside down family' in their book relating to the life histories of adult children of parents with learning disabilities. They did not find that children were called on to help more when their parents were more disabled; more important factors were lack of fathers' involvement and the availability of external support. Nor did the people they interviewed express feelings of resentment or loss if they had taken on caring responsibilities within the home.

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[1] Brooker wrote:

> *In Jelika's house, I came across her standing on a chair using a heavy knife to chop onions: as I moved towards her to intervene, her grandmother mildly stepped forward and tidied the chopped onions, leaving Jelika to continue chopping. (*Brooker, 2002: 51*)*

> *Role reversal or reverse dependency are not concepts that found any resonance in the memories or experiences of the now-adult children in our study....we must conclude that the upside down family is a myth* (Booth and Booth 1998: 168)

Research which is 'child-centred' and which positions children as active participants and co-constructors of their social worlds, has highlighted the contribution of children to their families, schools and communities (Alderson, 2000; Morrow, 1994). By conceptualising children as '*sentient beings who had the competence to provide emotional support as well as practical support to others'* Brannen and Heptinstall (2003: 190) elicited accounts from children describing their assessments of 'care', for instance as 'unconditional love' or 'connectedness to others' and their active engagement in care activities.

Moreover, encouraging children to be helpful and to take on responsibilities can be part of a discourse of child socialisation, rather than a discourse of disability and 'young carers' (Grue and Laerum, 2002: 679). Learning to perform domestic tasks and to take on certain obligations can be construed as a significant part of growing up and part of encouraging the development of qualities of thoughtfulness, kindness and responsibility. Although a number of the physically disabled mothers in Grae and Laerum's study took pains to avoid asking for help from their children, lest others make the assumption that they were 'exploiting' their children and treating them like unpaid personal assistants, others emphasised the benefits of encouraging their children to help:

> *They perceived that they had children who were able to see when other people needed a helping hand, and they interpreted this as an important value acquired by a child growing up with a disabled mother. They also stressed the value of the fact that their children learnt to be tolerant of differences. The mothers also reported that other people seemed to value their children for their considerate behaviour. This group of mothers contested the view that having responsibilities and acting responsibly has a negative impact on children* (Grae and Laerum, 2002: 680).

Grace takes a similar perspective in the following passage:

8.viii Grace, learning disability Social Worker

1	G:	So (.) they go together with the six year old
2	D:	Hmm
3	G:	They go together and it was fun
4	D:	Hmm
5	G:	Tidying up and cleaning the dishes (.) and they enjoy if and the six year old
6		was saying oh mum it's time to do the dishes (1) So they enjoy that (.) and
7		they're doing the dishes and they're interacting as well
8	D:	Right
9	G:	The child enjoys that (.) helping up their mum and the mum remembers that
10		and is proud of it (.) I remember I was speaking with this mum and I just said
11		(.) you've got to do this you know
12	D:	Hmm
13	G:	Because if you don't she won't develop and help you in future
14	D:	Hmm
15	G:	But if you're teaching them as they grow older they're beginning to help you
16		and they're beginning to take some of the responsibility from you.
17	D:	Hmm
18	G:	And that seems to speak to her (.) so when I came back to her she said yes
19		I remember you telling me that (.) they have to learn to help me when they
20		grow up
21	D:	Right
21	G:	And I said well how does that feel and she said oh that feels nice
22	D:	Right
23	G:	And she said I'm trying to teach them to help (.)
24	D:	Right
25	G:	I mean (.) the risk in that one is that would (.) would [would she
26	D:	[Yeah
27	G:	know not to give the child more than she can (.) take
28	D:	Yes
29	G:	(1) But (.) then if you're there you can always check on that and make sure
30		they don't give the child (.) more responsibility than they are capable of
31		handling at that moment

Grace positions the 'helping child' in this extract within a discourse of child development and child socialisation. Even though the child mentioned in the extract is only six years old, the mother is encouraged to start teaching her domestic skills so that she can help more in future '*you've got to do this you know...because if you don't she won't develop and help you in future* '(lines 13 and 15). There is an underlying assumption that it is reasonable for parents to expect children to develop helping skills and take on more and more responsibility as they grow up.

However, bearing in mind the negative connotations that accrue to the concept of 'child as carer' Grace is careful to avoid any imputation that getting a child to help might involve anything harmful or unpleasant for the child. She emphasises the idea that helping with domestic tasks is fun (line 3) and enjoyable (line 5) for the little girl. The child's assistance is not

an end in itself, it involves 'interacting' with the mother (line 7) which presumably the daughter will enjoy; moreover, within the discourse of child development 'interacting' is seen as an essential component of fostering intellectual and social skills (see Section 8.8). However, the spectre of the exploited 'child carer' lurks throughout this passage. Grace anticipates the argument that the mother would not know when to cease loading responsibilities on a child (and in anticipating it, Grace endorses it). In the end, it is the role of the professional to determine and to monitor how much responsibility is acceptable.

8.5 Family feelings; is love enough?

In this study, a sense of children as having autonomy and contributing positively to family life was largely absent. They were most often characterised as 'victims', whether victims of their parents' neglect and poor parenting, or of lack of support or structural inequalities. However, in Kelley's account, a rather different picture emerges, when Margaret is comforted by her nine year old son, Josh.

Extract 8.ix Kelly, family support worker

1	K	Something went wrong and Margaret was getting quite upset about it
2	D	Yeah
3	K	and Josh went round (.) and put his arm around (.) and hugging her and he
4		was saying it's okay: (.) with his arm round her and patting her on the back
5		which is (.) actually quite an adult way of doing things
6	D	Right
7	K	But that was (.) like offering comfort=
8	D	=Yeah
9	K	And um (1) you know (.) Margaret put her arm back round and it's like (.) it's a
10		natural response

Children in Brannen and Heptinstall's (2003) study supplied similar examples of offering emotional support and care to their parents. However, Kelley is aware that this is the sort of behaviour that would be expected of a parent, rather than a child, and signals her understanding by remarking on the unusualness of this action; she says it is 'quite an adult way of doing things' (line 5). Using Sack's (1992) methodology, 'offering

comfort' is a defining marker, or 'Membership Categorisation Device' relating to the category 'adult', not 'child'. Yet Kelly does not want to characterise this interaction as pathological, so to fend off this sort of interpretation, she emphasises the naturalness of the interaction (line 10). For what could be more 'natural' than mutual love between a mother and child? She is mobilising a potentially powerful gendered construction of motherhood as defined by the mother's natural and total love for the child, making motherhood a woman's 'ultimate fulfilment', the supreme physical and emotional experience available to women (Marshall, 1991).

The strength and persistence of the emotional bond between parents with learning disabilities and their children comes across in research undertaken with and by the adult children of these parents (Booth and Booth, 1997, 1998a; Ronai, 1997). This research has involved close and long-term involvement between researchers and the families being studied. In her article titled 'On Loving and Hating My Mentally Retarded Mother', Ronai described herself as a participant observer (1997: 419) of the process of growing up with a parent with learning disabilities. These researchers try to capture the complexity and ambivalence of intimate family relationships, while at the same time bearing witness to the efforts made by the parents to love and nurture their children, often against considerable pressure and opposition.

> *First and foremost, my mother loved me, and in her own way took responsibility for me. Inside that love, I believe, a seed of faith was planted, a blind unreasonable faith which informed me that although things were rotten now, they would be better in future* (Ronai, 1997: 429).

In an extended case study of the Spencer family, Booth and Booth (1994) also highlighted the pivotal role that Rosie, the mother takes as the focus and rationale for ongoing family life. They noticed that expressions of kinship and love between family members may not be expressed in words, or even necessarily in skilful execution of caregiving skills, but rather in long-term habits and rituals of companionship and concern. They cautioned, *Be wary of assuming that parents with learning disabilities do*

not have the same feelings of care and affection for their children as other parents or that their family bonds are weaker (Booth and Booth 1994: 112).

However, Mayall (1990) has argued that the emotional commitment that mothers have for their children is seen by childcare professionals as a necessary, but not sufficient component of appropriate mothering. Being a mother means not only 'caring about' children, but also 'caring for' them. Whereas mother-love, caring about children, is seen as so natural and unremarkable that it is seldom even mentioned, caring for children, 'tending' them, as a practical expression of love and concern is seen as the legitimate focus of professionals' monitoring and intervention. Caring about children, loving them is all very well, but by itself, simply not good enough:

Extract 8.x Brian, children and families social worker

1 2	B:	She couldn't care for them (.) which was a pity because (1) she did love them (.) but that isn't enough

Love as something existing within the parent, a feeling, might not necessarily be made overt or expressed in day-to-day interactions. After all, love is intangible, and unenforceable. As Alderson (2003) has pointed out, we can conceive of upholding children's rights to receive physical care, but cannot enforce any right to be loved. Therefore love must be put to work in the cause of children's wellbeing; caring about should be inextricably linked with caring for and meeting 'children's needs'.

Extract 8.xi Catherine, children and families social worker

1	C:	Because she was terribly attached to her children
2	D:	Right
3	C:	(1) I mean (.) she (1) I don't know (3) I mean
4	D:	[yeah
5	C:	[it was difficult (.) because: (1) I (.)
6		she could be quite damaging to the children=
7	D:	=Right
8	C:	She would say things like (1) especially when the assessment was going on
9		(.) she'd say (.) well either (.) she'd say in front of the two older children
10	D:	Hmm
11	C:	Well either I get the two babies or (.) I don't want any of you (1) and (.) stuff

12		like this which is like very (2)
13	D:	Right
14	C:	(.) But (.) but (1) I mean she loved them to bits (.) and she had (.) coped (1)
15		she had coped to a certain extent

The hesitations, and hedges in this passage (lines 3, 5, 12) suggest Catherine's discomfort in positioning herself as acknowledging the mother's love and attachment to her children, and at the same time being a witness to the mother's 'damaging' and hurtful comments to her children. She seems to 'flip' between the mother's perspective, being '*terribly attached*' to her children, who '*loved them to bits*' to the perspective of the children, hearing the mother's rejecting comments, which Catherine dramatises in a quotation in direct speech (line 11). Does this mean that this construction of 'mother love' must exclude ambivalence and preferences?

8.6 Parental love and children's needs

In this section I look in more detail at how participants constructed children's needs. In general terms, foregrounding 'children's needs' appears to remove the stress on parental characteristics and behaviour in themselves as influencing workers' decisions about the adequacy of the family environment. In this vein, Schofield argued

> *...the whole emphasis in the 1989 Children Act is less on what parents do and more on what children need, and the observable consequences of parenting in terms of the development of the child* (Schofield, 1996: 88)

Therefore, the argument against parents with learning disabilities is not focused on the parents' specific deficits (thus deflecting accusations of discrimination against these parents), but on their inability to meet their child's needs. Children's needs are constructed as objective, as requiring particular appropriate and sanctioned responses on the part of parents, and as paramount. I draw particular attention to participants' descriptions of children's need for stimulation, and for security and protection.

Extract 8.xii Leanne, residential family centre manager

1	D:	I mean (.) what sort of things have to be there for you to feel confident that this
2		family is going to work (...)
3	L:	Um (1) having (.) showing (1) being able to show warmth and affection
4	D:	Right
5	L:	It doesn't actually have to necessarily be that they are brilliant at getting down
6		on the floor and playing
7	D:	Hmm
8		Um (1) it's more (.) because that is something that you can help to teach over
9	L:	time
10	D:	Right
11	L:	But it's more that there is an awareness of the baby (.) an awareness that the
12		baby needs to feel secure and loved (1) um (3)

In line 4 Leanne starts to say that an essential component of parenting is *having* (feelings of) warmth and affection, but corrects this to assert that what is key is an ability in *showing* warmth and affection. Demonstrating this warmth and affection is also linked to an *awareness* (line 10) or understanding of the baby's needs to feel secure and loved. Whereas love is intangible, and ungovernable, children's needs are objective and observable. Leanne does not prescribe particular activities that the parents have to perform, and positions herself as critical to the argument that parents have to be expert baby entertainers (lines 5-6). Whereas such skills can be taught (line 8), the baby's needs are self-evident to the extent that parents should be aware of them without need for overt instruction.

Woodhead (1990) has written convincingly about the rhetorical power of conceptualising the requirements of childhood in terms of children's needs. 'Needs' appear to be objective characteristics of children themselves, which are established through empirical study by experts or close observation on the part of parents themselves. It is presumably this close observation which brings about the dawning awareness mentioned by Leanne in the passage above. Thus, in a similar construction to Leanne's (quoted above) a well-known childcare expert de-emphasises particular childcare skills, allowing her to fend off accusations of imposing her own personal philosophy of bringing up children on impressionable mothers, by linking her recommendations to children's needs: '*...this book*

is not designed to tell mothers how to rear their babies, but how their babies develop, and therefore what they need (Leach 2001: 18)

A discourse of children's needs positions the parent and the child in particular ways. Being 'in need' for children implies helplessness and passivity; the child must rely on others to address these needs. And the adult is located in a position of responsibility. The emotive force of needs language renders the adult culpable if the child's needs are overlooked.

Woodhead (1990) argued further that the rhetoric of 'needs language' masks what he contends are the culturally constructed nature of children's needs. Children are understood to 'need' particular inputs, in order to achieve particular developmental outcomes. Often the developmental outcomes themselves are unstated; nor is there any acknowledgement that these outcomes are likely to be specific to particular cultural and historical contexts. One might further argue that manner in which adults are required to meet children's needs, though also culturally specific, is often presented unproblematically as self-evidently right and obvious.

Extract 8.xiii Samantha, family centre worker

1	S:	So you're obviously looking for them to be able to feed the baby properly
2	D:	Right
3	S:	Clothe the baby appropriately (.) so not have it (.) you know [inaud] (.) which is
4		often (1) you know (.) parents find that quite difficult (.) difficult to judge what is
5		appropriate

Extract 8.xiv Liz, nurse specialist in child protection

1	L:	(3) They seem to have very limited understanding of a child's needs
2	D:	Hmm
3	L:	(2) They know a child needs to be fed and clothed (.) but sometimes the
4		clothing's inappropriate (.) the kind of feeding's inappropriate

Samantha and Liz construct similar arguments here. Parents must not only recognise and address children's needs for food and clothing, but must do this is ways that are appropriate. This word 'appropriate' like 'needs' carries a masked moral force. If something is appropriate it is correct and adequate to the task in hand, whilst avoiding the value

judgements entailed in describing something as 'right' or 'wrong'. Parents who do not understand which sort of food or clothing is 'appropriate' are lacking in judgement or have only *'limited understanding'* (Liz, line 3) of children's needs.

8.7 Children's needs come first

Not only must parents understand the correct and appropriate ways to address children's needs, they must also understand that children's needs are primary. The parent must prioritise the child's needs; adult needs and routines should be subsidiary to this. This might mean abandoning the shared routines and patterns of reciprocity which are part of a couple's life before they have children. In the first part of the extract below, Leanne does not offer any rationale for her conviction that children's needs must come first, implying that prioritising children is a self-evident necessity, even if it has implications for the smooth running of adult life. However, in the second part of the extract, Leanne adds force to her argument, suggesting that when parents put their own needs first, they compromise their child's safety.

Extract 8.xv Leanne, family centre manager

1	L:	Yeah: (1) as I was saying (.) couples seem to have (.) in our experience (.)
2	D:	[Hmm
3	L:	[It's much more difficult to get them to focus (.) on the [needs
4	D:	[Right
5	L:	Of their child
6	D:	Okay
7	L:	What they want to do is (.) they want to make the baby to fit the routine that
8		they have learnt (.) instead of (.) being able to look at how the baby's needs
9		have got to be met
10	D:	Right
11	L:	And that they need to (.) um meet their needs around that (1) the baby's
12		needs (...) Um (3) and so you have babies placed in very dangerous
13		situations (1) um (1) because the parents are seeking to get their own needs
14		met (.) without (.) consideration for the baby's

Catherine, below, makes a similar point. Adult preferences should come second to children's enjoyment and 'need' to play.

Extract 8.xv Catherine, children and families social worker

1	C:	I used to say (.) why don't you take them to the park (1) I mean (.) there was
2		an adventure playground sort of (.) literally (.) I could see it out of her flat
3	D:	Right
4	C:	And she'd say (.) it's <u>boring</u> (1) I <u>hate</u> the park
5	D:	Huh [huh
6	C:	[And I'd say (.) well (.) every parent hates the park (.) I've stood there in
7		January (.) just one more swing [((laughs))
8	D:	[((laughs))
9	C:	I mean you do it because the kids <u>enjoy</u> it rather than keeping the kids indoors
10		all day
11	D:	Right
12	C:	But (.) um (.) that's what she would do and wouldn't think of (1) well they need
13		to play or run around

Catherine makes the mother's objections seem unreasonable, by emphasising how near the playground is, and by normalising the mother's sacrifice by asserting that *every parent hates the park* (line 8), including Catherine herself, but will submit herself to the worst extremes of weather for the child's benefit. Even the child's rather unreasonable insistence (*just one more swing,* line 7) – not a 'need', surely – is treated indulgently with a wry laugh.

Leanne and Catherine are advancing a norm of parental behaviour which links 'putting children's needs first' to children's safety and normal development. In a similar manner, Tizard and Hughes (1984) praised 'sensitive mothers' for advancing their child's development by turning household chores into learning opportunities, putting the child's developmental needs before the mother's domestic routines and responsibilities. 'Sensitive mothers' (usually middle class) responded patiently to their child's interruptions into their domestic chores, which were only pursued if they could be turned into 'child-centred' learning experiences. In homes ruled by this 'domestic pedagogy', no opportunity for advancing child development is lost. Walkerdine and Lucey (1989) have critiqued this emphasis on 'domestic pedagogy' by arguing against pathologizing of working class homes where these practices do not hold sway. The 'insensitive' working class mothers who insist on finishing their chores without interruption have other priorities concomitant with less privileged social and economic position. Moreover, Walkerdine and Lucey

(1989: 23) have pointed out the cost to the middle class mother, who '*...makes her home, her everyday life, into an assault course of developmental tasks'.* These 'sensitive', self-sacrificing mothers have little time to address their own needs, because of their submission to the 'pervasive regulative practices' of domestic pedagogy (Pitt 2002).

Therefore, this construction of children's needs positions the child and the parent potentially in conflict; what advances the needs of one is boring, even hateful to the other. What might represent routine, predictability and control to one, is dangerous and stultifying to the other. Family life is structured with parents and children in opposition, but with parents obliged to forgo the advantages of their superior strength, knowledge and power, and to put their children first.

8.8 The developing child: the child as potential

Not only must parents have an awareness of children's needs, which they respond to as a matter of priority in an 'appropriate' way, they also need to time their interventions with their children in line with the child's developmental 'stage'.

Extract 8. Sue, Health Visitor

1	S:	whether she is going to feed it in the appropriate way (.) the right foods
2	D:	Hmm
3	S:	You know (.)
4	D:	[Yeah
5	S:	[And understand (.) that from about six months onwards you start (.) to start
6		changing to lumpy foods (.) the natural progression (.)
7	D:	Right
8	S:	Or does someone have to be (.) reminding her all the time of different stages
9		(.) which she's not going to get (.) in a way from reading leaflets and books
10		which other mums would do

Sue describes moving from feeding one kind of food to another should happen in line with the *natural progression* (line 6) of child development. The child in this construction is what Dahlberg et al. (1999: 46) identified as '*The Child as Nature – the Scientific Child of Biological Stages'.* According to this view, children are born with inherent capabilities which

unfold with age according to universal stages of child development. Aspects of children's functioning are split off and labelled separately as physical, social or emotional development, with little understanding about the interrelationship of children's skills or the social context in which all development takes place (Burman, 1994). Moreover, the direction of the trajectory is always assumed to be towards greater autonomy and independence on the part of the child, and more complex skill.

Extract 8.xvii Pat, service broker

1 2 3	P:	Whenever she's got Louise she's out with her in the pram (.) which doesn't help Louise's physical development (.) because (.) she hasn't learnt to crawl or to walk yet

These stages are revealed to parents by experts in child development in the sorts of books and leaflets that Sue mentions. Parents need this sort of guidance because each developmental stage has particular challenges and problems associated with it. Mayall (1990a) suggested that health visitors see it as their role to warn parents in advance about the demands of the stages the child is going through, so they can adopt the appropriate coping and management strategies. Parents need to be primed to provide particular types of input in line with the child's developmental stage. Failing to provide the right sort of input delays the child's progress along the natural developmental trajectory.

Extract 8.xviii Sue, health visitor

1 2 3 4 5	S: D: S: 	Um (1) and if she's just going to be left to get on with it (.) I mean (.) this child is not going to reach its full potential Hmm Because it's not going to have the stimulation or (.) perhaps even the care that it ought to have

Thus, the child is viewed as having the potential to develop along 'normal' lines, but needing the right kind of input in order to help this along. Mayall's (1990a) study of health visitors and mothers suggested that health visitors tended to promote purposeful 'stimulation' of the child by the mother as essential, particularly for the child's linguistic development. Mothers had the responsibility to take every opportunity to stimulate their

child's speech or the consequences would be that the child would not reach its full potential.

> *For most health visitors, however, children are projects requiring the full time presence and active intervention of their mothers. Essentially they aim to improve the mothers' willingness and ability to develop their child's potential, within their existing social and economic circumstances* (Mayall 1990b: 382)

However, even in this study of 'normal' mothers, health visitors were not confident that mothers could be relied on to impart the required amount of stimulation and needed constant reminding. Similarly, Beatrice in the passage below mentions that 'so-called' (line 7) normal parents in her area are not competent in responding to and stimulating their babies.

Extract 8.xix Beatrice, health visitor

	B:	Plus (.) um (1) their own interaction with the child (.) [with the children
2	D:	[Hmm
3	B:	U::m (1) how they just generally speak to the child
4	D;	Yeah
5	B:	I mean a lot of parents find it difficult (.) er to have (.) to talk to babies at first
6	D:	Yeah
7	B:	So-called normal parents find that difficult (.) but they (.) they find (1) there's
8		an extra hesitancy (.) if you like
9	D:	They don't seem confident (1) o:r=
10	B:	=No (1) they (.) they just say (.) they just say to you (.) well he can't talk back
11		(.) can he
12	D:	Right
13	B:	That sort of manner (1) um (.) there is that sort of very basic knowledge (.)
14		that yes (.) babies can't respond (.) but there's the other level (.)
15	D:	Right
16	B:	If you move up a level (.) if you speak to babies or communicate (.) um you
17		get the eye movement (.) you get the smiling (.) then that develops
18	D:	Yeah
19	B:	And it's teaching about child development in the sense that (.) these (.) the
20		child smiling (.) is a form of communication
21	D:	Hmm hmm
22	B:	So it's teaching those basic skills (.) that leads me obviously to [laughs] feeling
23		a little bit concerned not everything is going in
24	D:	Right
25	B:	(1) But having said so (.) possibly (.) I would imagine that this reflects the
26		area (.) in that a number of clients in this area (.) you've got to constantly
27		reinforce that kind of message

Beatrice describes parents resistant to her 'expert' knowledge of early language development, derived from Bruner's research on mother-child dyads, which stressed the importance of parent's attribution of

communicative intention to the baby (Burman, 1994). According to this formulation, through a process of 'scaffolding', adults pattern their interactions with young children through turn-taking to frame and structure the child's actions such as sucking and looking, which do not obviously have a communicative purpose. I offer the possibility that the parents' percieved shortcomings might be due to lack of confidence (line 9), but Beatrice focuses on their lack of understanding and the simplistic reduction of communication to talking back (line 10). She insists that babies will respond with looking and smiling if talked to. Her use of an *if...then* construction (lines 15-16) implies that children will not develop unless spoken to.

Beatrice's use of the term *so-called normal* (line 7) here is interesting. She is unpacking the term normal into its different meanings – normal as usual or typical and normal as natural and exemplary. In fact the 'so-called' normal parents who are in the majority where Beatrice works who are not British in origin or who live in circumstances of social deprivation and social exclusion do not do a good job of 'stimulating'. *'in that a number of clients in this area (.) you've got to constantly reinforce that kind of message (line 26-27)'*

Like Walkerdine and Lucey's (1989) working class mothers, they are not sufficiently 'sensitive' to their children's needs. They do not work hard to organise their communicative interactions with their children, and need constant reinforcement to create playful, constructive opportunities to enhance their child's language development from health visitors. However, an analysis more sensitive to the constraints and demands associated with particular class position might understand the ways of talking to children that Beatrice advocates as culturally and class specific.

> *The priority accorded to play divorces language learning from other everyday caregiving contexts, and presents a sanitised and idealised picture of women at home with no commitments other than to devote themselves to extending their child's vocabulary* (Burman 1994: 116).

In this chapter I have argued that parents with learning disabilities are seen as endangering children's wellbeing in specific ways. The way that they are socially constructed, particularly their attributes as deficient adults means that professionals worry that their children's perceived 'needs', in particular for a carefree childhood and for intellectual stimulation are not being met. Thus, the ways in which 'parents', 'childhood' and children's needs were constructed placed certain responsibilities on the parents with learning disabilities, which professionals felt the parents were likely to fail to fulfil.

Chapter Nine: Risk, Safety and Protection

9.1 Introduction to Chapter Nine: children, parents and the 'Risk Society'

In this chapter, the obligations and responsibilities of parents are examined further with reference to discourses of risk, safety and protection. I address the questions of how and why ensuring children's safety becomes a key task for parents and for professionals. This preoccupation creates subject positions for children, parents and professionals.

I also consider how local considerations of children's safety constructed by my participants relate to wider theoretical conceptualisations of risk as a central constituent of contemporary society, a characterisation of modernity particularly associated with the writings of Giddens and Beck (Beck, 1992; Giddens, 1990; 1991). A brief overview of these theories follows, and I return to them at the end of the chapter with an evaluation of their relevance for understanding the way that relationships between these professionals and parents are constructed.

Beck and Giddens have been very influential in arguing for the dominance of concerns about risk in contemporary social life. Both advance claims that the disintegration of traditional social arrangements has undermined our collective sense of certainty and predictability. In contemporary 'risk

society' we are all confronted by the unintended consequences of rapid social, economic and environmental change. These consequences may include the instability of family arrangements, insecurity of employment, pollution and environmental destruction. All of these have heightened perceptions of risk and intensified searches for strategies of risk prediction and management.

> *Class societies remain related to the ideal of equality in their developmental dynamics. Not so the risk society. Its normative counter-project, which is its basis and motive force is safety....Whereas the utopia of equality contains a wealth of substantial and positive goals of social change, the utopia of risk society remains peculiarly negative and defensive. Basically, one is no longer concerned with achieving something 'good', but rather with preventing the worst* (Beck, 1992: 49, emphasis in original).

Beck has characterised risks in modernity as having particular characteristics; they are global, they are often imperceptible and incalculable, they are abstract and therefore *particularly open to social redefinition and social construction (Beck, 1992: 239)*

A concomitant feature of the 'Risk Society' is **individualization**, whereby responsibility for managing risks and ensuring one's life trajectory (Giddens, 1991) coheres into the satisfaction of one's innermost aspirations and potentialities, and becomes an individual's personal responsibility. Another important feature is a shift in lay people's attitude to experts and expert knowledge. Giddens has argued that the reflexive nature of modern life, whereby all knowledge is seen as contestable and in a process of constant revision in the light of incoming information entails *the routine contemplation of counterfactuals* (1991: 29). Beck suggests that this epistemological orientation has led to a widespread scepticism towards the truth claims of experts. According to Giddens, the defensive reaction of experts has been to resort to greater degrees of specialisation and bureaucratisation, in order to re-establish relationships of trust.

These ideas have proved fertile ground for social scientists of childhood, the family, and professional interventions into family life. Parton et al.

(1997), Parton, (1998), Anglin (2002) and Scourfield and Welsh (2003) have argued that in a risk society, where professionals feel under scrutiny, a focus on risk assessment and risk management has come to dominate professional practice to the exclusion of work aimed at supporting children and families in more positive ways. Scott et al. (1998); and Kelly et al., (1998) have examined how parents' concerns about risk management have become central to everyday experience of children, often in constraining and limiting ways.

9.2 The discursive construction of 'safety'; two approaches

In the next two extracts constructions of 'safety' and 'threat' are developed as key considerations in evaluating parenting ability, though with the constructions being given a different ontological status by each speaker.

Extract 9.i: Liz, nurse specialist in child protection

1	D:	What do you think are the most important bits (1) I mean (.) if you (.) if you've
2		got concerns about a family then (.) which (.) which bits would you think well
3		(.) these bits have to be there (.) um (1) you know (.) if (.)they're not there
4		really it's a (.) hopeless case
5	L:	(1) Well (1) it just depends on whatever
6	D:	Hmm
7	L:	I mean (.) the priority is to keep (1) you know (.) keep those children safe
8	D:	Right
9	L:	(.) And that's got to be first and foremost
10	D:	Right
11	L:	Um so if anything (.) anything is a threat to that child (.) that children's safety
12		(.) that has to be addressed (2) if that can't change then (.) other things may
13		have to be introduced

Extract 9.ii: Kelly, family support worker

1	K:	Because no one tells us these things (.) we're left to decide for ourselves to
2		some extent
3	D:	Yeah
4	K:	(1)I think one exception is (.) safety
5	D:	Hmm
6	K:	Because I notice (.) sort of every thing you go to(.) like um they go (.) are the
7		children safe
8	D:	Right
9	K:	Because (.) um (.) Sally and Emma were on the At Risk Register
10	D:	[Okay
11	K:	[So when it was coming to them (.) being taken off (.) it it was like (.) [are they
12		safe
13	D:	[Yeah

14	K:	You know (.) what are the safety issues
15	D:	Right
16	K:	And it was like (.) oh (.) okay (1) and the one for Charlie (.) it was like (.) well
17		(.) he is safe (.) but he is lacking in this this and this
18	D:	Right
19	k:	But it was (.) so from them (.) I've learnt what is expected (.) that that you have
20		to ensure safety (.) like (.) [crossing the road,
21	D:	[hmm
22	K:	Knowing your own phone number (.) you know how to contact the police (.)
23		and it's that kind of practical thing (.) [and
24	D:	[Does that make sense to you (1) or:: (.)
25	K:	Um (2)
26	D:	You sound a bit (.) sceptical about it
27	K:	Yeah (1) I um (.) it's quite strange that they don't do (.) at the end of the day (.)
28		that's what gets you off the At Risk Register whether you are safe or not
29	D:	Hmm
30	K:	It's not (.) um (.) with Charlie it was a big thing about his emotional wellbeing
31		wasn't
32	D:	Hmm
33	K:	He was being neglected (1) Um (2) so it is quite interesting that the (.) At Risk
34		Register it didn't matter if they were being neglected emotionally
35	D:	Yeah
36	K:	That was okay (.) that was ignored (.) but but maybe that was because they
37		knew they were loved and weren't being emotionally neglected
38	D:	Right
39	K:	But with Charlie it was (.) yes he is safe and that was acknowledged (.) was
40		brought out (.) was discussed (.) but (.) [his emotional wellbeing
41	D:	[hmm
42	K:	Was being neglected
43	D:	Hmm (.) [right
44	K:	[So it's quite interesting from those (.) sort of things (1) so (.) from
45		that I have learned what is required from me as a worker

Each passage relates to the primacy of ensuring children's safety as a requirement of both parents and workers for human services. Children's safety, particularly the safety of their bodies, is seen as the sine qua non of adult relationships and responsibilities towards children. Liz says that children's safety is the *priority* (line 7), and *first and foremost* (line 9). Kelly states that although other issues might be left to a worker's discretion *the one exception is safety* (line 4); concerns about safety turn up at *every thing you go to* (line 6).

However, if we look in more detail (and Edwards and Potter's 1992 discursive action model is useful here) at how the speakers orientate themselves rhetorically to the construction of 'ensuring children's safety' in each passage, we can see that they are accomplishing rather different things through their use of different discursive devices. Liz uses a **reifying** discourse (Potter, 1996) to construct the paramount importance

of ensuring children's safety as a thing. It is *'the priority'* (line 7), which has the attributes of being *'first and foremost'* (line 9). Equally the idea of *'a threat'* to children's safety is introduced as something that is solid and factual, that has actuality in the world. The threat is a thing that has to be *addressed* (line 12), it has to change, or other unspecified, though probably drastic, consequences will come about. This reifying is an effective form of **stake inoculation** (Potter, 1996); that is, a device which can fend off imputations that a speaker puts forward certain views because of personal opinion, self interest or professional bias. Liz constructs children's safety and threats to it as real things needing urgent consideration, which all workers need to talk about and take action on, irrespective of their individual opinions or motivations.

Moreover, this discourse of risk is one that allows for categorical and unambiguous statements. In Liz's first answer to my question about what she thinks are the essential elements of parental input to children she appears to be embarking on a way of tackling the issue that takes in account different factors and circumstances as well as her judgements of their importance: *'(1) Well (1) it just depends on whatever'* (line 5). However, she draws back from this kind of conditional talk in her next utterance: *'I mean (.) the priority is to keep (1) you know (.) keep those children safe'* (line 7).

Constructing 'risk' as a thing allows for the imputation that it is something objective and uncontroversial. An even clearer example of this can be seen in a recent newspaper article where the author, a local authority councillor with responsibility for children's services defended the decision of social workers to remove the children of parents with learning disabilities in a controversial case which attracted a lot of media attention:

> *Parents may be unable to cope with the tasks of parenting for many reasons: from depression or addiction, to learning difficulties or domestic violence. We could never set a simple test of what is an acceptable level of parenting. We could no more set an IQ level that defines an 'acceptable parent' any more than we can say how*

> *depressed is too depressed to look after a child. There is only one question to ask: is the child at risk of significant harm? If the answer is yes, we have a legal, and moral, obligation to act* (Chapman, 2005).

The author has assumed that any attempts to define the essential components of parenting tasks or the important characteristics of parents themselves will be compromised as simple/simplistic and relying on personal judgement, whereas identifying risk is presented as a straightforward yes or no decision leading to clear guidelines for action from staff (taking children into care).

I shall look in more detail at how other speakers elaborate on the nature of children's safety and threats to it and how their constructions link to other constructions in the wider social context. But first I suggest that Kelly orients herself differently to these issues. In contrast to Liz, she constructs an **ironizing discourse** (Potter, 1996) about children's safety and how it is managed. An ironizing discourse can be understood as one where the speaker positions him/herself at 'one remove' from arguments presented, without making any personal investment in the veracity of the account. This approach treats accounts or descriptions as versions of reality which are products of particular interests or strategies. As Potter (puts it), this orientation '*undermines the literal descriptiveness of versions; it turns the material thing back into talk that is motivated or distorted*' (Potter, 1996: 107).

Using an ironizing discourse also relates to issues of **footing** (Goffman, 1981). It places the speaker on a more distanced footing from the events or descriptions she reports, as a way of managing her personal or institutional responsibility for the nature of the report.

Kelly achieves this is a number of ways in her description of how safety is prioritised at child protection conferences. She uses reported speech to voice the concerns about safety at line 6 '*they go (.) are the children safe*' and lines 15-16 '*(.) it was like (.) well (.) he is safe (.) but he is lacking in*

this this and this'. In fact, after being cued in by Kelly's long pause at line 24, the two of us together construct Kelly's position as 'sceptical' (lines 23-27). Kelly distances herself from the importance of safety as a real thing that inevitably stirs all parties into action. She has learned to highlight safety issues, because that is what she has found is required of her as a worker (line 44), but the distancing devices she uses suggest that she wants to be seen as someone who does not necessarily accept the views about ensuring safety that are common currency in child protection procedures. Indeed she argues that the child's emotional wellbeing is ignored while safety is exhaustively focused on. Here her use of a three part list in lines 38 -39 (*that was acknowledged (.) was brought out (.) was discussed*) gives a sense of the completeness and thoroughness of the treatment of safety concerns (Jefferson, 1990).

Kelly implies that being concerned with safety is what is expected and required of her by others (those who are in charge of the At Risk register – namely social workers); it is their preoccupation, not hers. Kelly's discursive devices are effective in allowing her to bring off the implication that she has insight into the interests and stakes of others who construct safety as paramount, while also maintaining her position as a reporter of integrity and independence who judges for herself what is important (but nevertheless does what is required). I have already examined this construction of 'safety' as a preoccupation of social workers and traced its history and provenance through the recent political and social context in Section 2.3.

9.3 'As the Child Grows Up': a developmental perspective on risks

The previous chapter looked in more detail at the way that overarching discourses of **developmentalism** structure understandings about children. Children are seen as immature, incomplete, and progressing through biologically bounded 'stages' of development towards adulthood. I examined how children's minds are seen as needing special sorts of adult

input. Without 'stimulation', delivered with sensitivity and skill, professionals worry that children will fail to reach their intellectual 'potential'.

In this chapter I examine how discourses of safety and protection focus on children's bodies. Children's bodies are seen as vulnerable or unruly, requiring nurturing in special sorts of physical environments as well as surveillance and control. Although it is the environment inside and outside the home that is understood to be bristling with dangers, the individual parent is seen to be responsible for modifying and maintaining a suitable environment, free of hazards.

Using a developmental framework, participants suggested that the normal trajectory of child development exposes the growing child to dangers which it is the parent's responsibility to anticipate and contain.

Extract 9.iii: Chris, health visitor

1	C:	Yes, I mean as the child grows up (.) um (1) the safety of the child when it
2		starts playing
3	D:	Like=
4	C:	= I mean when it starts crawling and that sort of thing (.) whether she is going
5		to be aware that she needs to move things out and about

Extract 9.iv: Liz, nurse specialist child protection

1	L:	If we are thinking about the child (.) about (.) reduced risk for the child (.) it
2		might be that we identify particular points at which we think suddenly an
3		increased risk (.) [where (.)
4	D:	[Right
5	L:	Suddenly the child development proceeds
6	D:	Hmm
7	L:	Suddenly gets mobile
8	D:	Yeah
9	L:	So (.) you might find that about the age of seven (.) eight nine months (.) when
10		crawling starts you have to go and put in quite intensive input about home safety

In constructing a narrative about the risks during child development, Liz emphasises the dramatic discontinuities in the way that children acquire new skills, by repeating the word, 'suddenly' (*suddenly an increased risk...suddenly child development proceeds...suddenly gets mobile*). Not

only are hazard and danger implicit in child development, but they appear dramatically and without warning for the unwary parent. In this construction of 'normal risks of child development' the professional, who has relevant expert knowledge of child and the 'stages' of growth through which they proceed is called to be active warning of emerging dangers, and Liz uses active, agentive language to signal this. Moreover, she uses the plural *'we'* (*we identify...we think*) to suggest that identifying risks is a matter of consensus based on shared professional practice and specialist theoretical knowledge which allows her to be quite specific about expected ages for children to reach particular milestones such as crawling (*seven (.) eight nine months*, line 9).

These discussions of *home safety* construct the home of parents with learning disabilities as a physical place which has to be made safe for the developing child. Other research has suggested that there is an assumption by parents that the home is a already a place of 'safety' for children, compared with the outside world, where the risks are dramatic and frightening: assault by 'predatory paedophiles', traffic accidents, exposure to drugs and crime (Hood et al., 1996; Scott et al., 1998). Kelley et al. (1998) found that parents' worries externalised dangers to children as existing outside the home, particularly worries about child abduction, violence, pollution and local schools' standards of education. Consequently, the distinction between home as a 'safe haven' and the social world outside as risky and dangerous was intensified.

However, there seems to be a different emphasis when these professional participants talk about the home. Where there is a parent with learning disabilities the home becomes a place of danger in itself, since, in the eyes of some participants, these parents cannot be trusted to take 'correct' steps to ensure home safety, steps such as 'childproofing' the home; as Chris puts it, taking measures to *move things out and about* (line 10). The professional therefore is required to act to reduce risks, *put in quite intensive input* (Liz, line 10) so that the parent transforms the home environment into a place of safety.

Mayall (1993) has already noted the way that in interactions between child care professionals and parents, 'the home' was constructed as an 'intermediate domain', not quite private and not quite public. 'Home' can be a sanctuary from state intervention only insofar as the activities of family members and their aspirations and desires accord with dominant social agendas. In her research with health visitors, Mayall concluded that their assumption was that *'mothers should accept that their home was not entirely private, but an arena where the welfare state had a place'* (Mayall, 1993: 80).

9.4 Children as threats to their own safety

Not only does the normal course of development (as a kind of pathway that children travel along) expose children to dangers, but also their own natures can be constructed as tending towards risk-taking as Catherine suggests.

Extract 9.v: Catherine, children and families social worker

1	C:	Well (.) I mean (.) basic safety in the house
2	D:	Right
3	C:	You know (.) not children hanging out of the window (.) and you know (.)
4	D:	[Yeah
5	C:	[And left unsupervised (1) I don't know (.) just (1)
6	D:	Hmm
7	C:	Well it depends: really (.) because you are talking about (.) different ages

In the longer extract below, Liz describes a typical scene when parents with learning disabilities bring their children to the health visitors' child monitoring clinic.

Extract 9.vi: Liz, nurse specialist child protection

1	L:	And I think (.) any parent finds it difficult to actually set boundaries and think
2		about how they are going to discipline their child (.) and guide their child into
3		doing things that are safe (1) and not things that are (.) unsafe (.) but I think
4		parents with learning disabilities find that particularly difficult
5	D:	Right
6	L:	So (.) um (.) for example (.) both the families for example (.) when they come
7		to the clinic (.) the children run riot

8	D:	Hmm
9	L:	And they raid the fridge in the doctor's room (.) and they nearly drown
10		themselves in the little pool that's in the council estate outside which should
11		be boarded up [laughs]
12	D:	[laughs] yuh
13	L:	And the children aren't really kept safe
14	D:	Right
15	L:	And the parent doesn't perceive that it's their responsibility to do so
16	D:	Yeah
17	L:	I asked him to stay here (.) therefore it's his fault (.) sort of thing
18	D:	Right
19	L:	What can I do (.) I haven't got eyes in the back of my head

Liz here uses the effective rhetoric tool of **active voicing** (Woolfitt, 1990; Potter; 1996) using what she offers as reported pieces of speech (lines 17 and 19) as a way of reinforcing her argument that these children are not 'kept safe'. Potter (1996: 161) explained that active voicing *'brings into being separate corroborating actors, who, like ventriloquists' dummies, seem to have life, opinions, and personalities of their own'.*

Here the putative speaker is 'the parent' (line 15) who confirms Liz's contention that children are not being kept safe, by offering weak and unconvincing justifications for failing to prevent children's potentially risky behaviour (*I asked him to stay here (.) therefore it's his fault...What can I do (.) I haven't got eyes in the back of my head*). Liz is not claiming that she is directly quoting a particular parent. The phrase 'sort of thing' (line 15) alerts us to the idea that these are the kinds of comments Liz hears again and again. The attributed phrases are taken as emblematic of what these kinds of parents generally say.

However, how can Liz be sure that we are going to hear the justifications offered by 'the parent' as unconvincing? 'The parent' (with learning disabilities) seems to advancing the idea that children should listen to their parents' instructions or face the consequences. The child is therefore assumed to have agency and some responsibility for his own well being. It is *'his fault'* if he (sic) is involved in an accident. The parent should not be expected to be able to monitor the child's every move (*'I haven't got eyes in the back of my head'*).

The parent's arguments can be read as rather feeble excuses because Liz is working from the premise that the individual parent should be held accountable for 'keeping children safe'. This is presented as an obvious and observable 'fact' that the parent should '*perceive*' (line 15). So Liz progresses from constructing 'parents with learning disabilities' at the beginning of the passage as fitting into the general picture of parents who are struggling to provide boundaries and discipline for their children, but who have extra difficulties with this (perhaps because the task involves cognitive processes like thinking and guiding mentioned in lines 1 and 2) to imputing that these parents do not even see the necessity of making the effort.

Chapter Eight looked at how the parental responsibility involved parents having to ensure intellectually nurturing and 'carefree' environments for children. Where the focus is on risk and danger, responsibility means protecting children not only from everyday hazards, but also from their own and other children's risk-taking and risk-seeking behaviours. Children are positioned not only as *victims*, but also as *threats*, to their own wellbeing, and to public order. It is the spectre of the out of control, lawless child that Liz evokes by using terms like '*run riot*' (line 7), or '*raid*' (line 9).

There seems to be another discourse creeping into Liz's talk; the idea that there might be a collective, societal-level responsibility to ensure safe environments for children where they can play and explore. Liz admits that the little pool on the council estate which presents a drowning hazard should be boarded up (lines 9-10). However, her ironic laugh in line 11 suggests she regards this more as a fond hope than a matter to be tackled seriously, returning to the theme of individual parental responsibility (line 13).

9.5 Neglect: failing in the service of children's bodies

The risks described here are defined as the exposure of children to hazards in their everyday environments, in other words failures to protect children, rather than actual physical or sexual assault. In child protection terms this would fall into the category of neglect – a rapidly expanding concept in child protection literature and practice. According to government statistics there has been an increase in the proportion of children on child protection registers because of 'neglect' from 29.5% in 1994 to 39% in 2002 so that this has now become the highest category of child protection registration (Department of Health 2003).

Neglect is often conceptualised as a failure to service children's bodies, particularly in the areas of feeding and cleaning.

Extract 9.vii: Brian, children and families social worker

1	B:	Cos what happened she went to this house (inaud.) it was a really nice three
2		bedroomed house and the children wrecked it completely within a week
3	D:	Yeah
4	B:	You wouldn't have known it was the same house (.) It was filthy (.) it was (.)
5		disgusting (.) the toilet was blocked (.) there
6	D:	Ergh
7	B:	There was shit (.) there was (.) faeces and urine leaking through the kitchen
8		ceiling from the bathroom (.) and the children were just completely and utterly
9		out of control=
10	D:	=Right
11	B:	Completely

Brian uses powerful rhetorical devices to emphasise the unacceptability of the physical environment and the level of dirt, mess and chaos. He uses contrast and extreme case formulation to describe a house transformed from *really nice* (line1) to one wrecked *'completely within a week'* (line 2). His description of *'shit'*, which he even more graphically rephrases as *'faeces and urine leaking through the kitchen ceiling'* (line 7) evokes strong feelings of horrified disgust. Such arguments brook no response from me further than an appalled exclamation (line 6). Moreover Brian implies a

link between the disordered, desecrated house and the disordered and unregulated children.

Extract 9.viii: Catherine, children and families social worker

1	C:	And the children were eating (.) frozen peas (.) the two little ones were just
2		going to the fridge and getting frozen peas out of the freezer and (.)
3	D:	[Hmm
4	C:	[There was like mouldy old cake on the floor (.) they were eating that

Also in this extract, Catherine refers both to the unregulated children, who just go and help themselves to inappropriate foods[1] from the freezer, and the disordered and dirty house, where mouldy cake lies on the floor.

Why this emphasis on mess and dirt? Participants would justify this attention in terms of hygiene and protecting children's physical wellbeing and their overall health. Catherine refers to common sense understandings that eating mouldy food is likely to make you ill. Brian makes this link explicit:

Extract 9.ix: Brian, children and families social worker

1	B:	She had difficulty keeping the house at an adequate standard of hygiene, so
2		the children would have diarrhoea and stuff a lot.

Perhaps, even more importantly, dirt and mess can be perceived with our senses. The presence of dirt is physical, incontrovertible proof of parental shortcomings. In general terms the maintenance of a clean home (and the provision of 'healthy food') is part of parents' responsible care of children's bodies, and the success or failure of this provision is assumed to inscribe itself in the child's physical presentation – how clean, how fat or thin. In short, Scourfield argues that the reason that the dominant neglect discourse is concerned with the servicing of the child's body is because bodies provide

[1] Although I remember reading and following some childcare advice when my own children were little recommending giving frozen peas to young children as a healthy, vitamin-packed snack, preferable to sweets and crisps. My younger son is still particularly partial to a handful of frozen peas.

> *easy evidence in a system that is based on the gathering of evidence and the management of risk. They are tangible and concrete in a climate of risk, insecurity and uncertainty. And they are visible signs of the quality of mothering* (Scourfield 2002: 380).

9.6 Risk as professional jeopardy: 'enough to cover their backs'

At this point, I would like to return to my description of Kelly's discourse as ironizing (see Extract 8.ii), where risk is not so much a physically observable or measurable thing which endangers children's wellbeing, but more a construction linked to a particular social and political climate that endangers workers. This construction looks at risk from the perspective of professionals, particularly social workers, involved with children and families. Concerns about possible risks to children are seen to be at the top of professional agendas, and inform their practice and priorities. Ensuring children's safety is understood to be the key outcome for workers, against which all their work will be judged.

Extract 9.xii: Carol, advocate

1	C:	But it's convincing children and families and care management
2	D:	Hmm
3	C:	That there's enough for them to cover their own backs
4	D:	What do you think their concerns are (.) what do you think is the key issue that
5		has to be (.) okay
6	C:	(.) Baby's security
7	D:	Right
8	C:	I think that comes first every (.) everywhere
9	D:	Yeah
10	C:	And unfortunately it's seems to (.) the first inclination is that the baby will not
11		be secure unless we prove other wise

In this construction, risks to children are intrinsically linked to risks to professionals; professional reputations are vulnerable in contexts where there are concerns about children's safety. Professionals are seen as needing to safeguard themselves against accusations that they have down-played or ignored possible risks. Therefore they take the stance towards parents on their case loads of 'guilty until proven innocent'.

Carol suggests that it is the responsibility therefore of parents with learning disabilities and their advocates to allay workers' anxieties about children's' safety so that workers' feel that they could not be accused of incompetence. The phrase, *enough for them to cover their own backs* (line 3) suggests that professionals feel they need constantly to defend themselves and their actions, with the unspoken threat that they may face judgement for their decisions, either in a court of law, or pilloried in the pages of a tabloid newspaper.

9.7 Subject positions within discourse of risk and protection

One way of positioning workers in this climate of wariness is to describe them as simply blinkered and prejudiced.

Extract 9.xii: Leanne, residential family centre manager

1	L:	And so you feel (.) in a way (.)
2	D:	Yeah
3	L:	That the odds are stacked against the family from the start (.) because the
4		local authority has written them off as being (.) non-copers (.) that (.) that
5		they're just not going to make it
6	D:	Hmm
7	L:	Um (1) it doesn't (.) it doesn't affect us (.) too much (.) [it doesn't] effect us in
8		the
9	D:	[Right]
10	L:	Way that we work
11	D:	Hmm
12	L:	But (.) you feel that before we even start this piece of work (1) there is a
13		loading against the family um (.) that you're going to have to prove twice over
14		that they are capable

Extract 9.xiii: John, advocate

1	J:	The story was written in advance
2	D:	Hmm
3	J:	She was never [going to be able to
4	D:	[hmm
5	J:	As far as the authorities were concerned
6	D:	Hmm
7	J:	Er (.) be supported to have her children
8	D:	Hmm
9	J:	Erm (.) or at least that's how it felt
10	D:	Hmm
11	J:	So it was incredibly frustrating

Both participants use the metaphor of a story being pre-written when it comes to parents with learning disabilities; that there is only one narrative for these parents, which highlights parental failure and minimizes expectations of support. The imputation that there is an assumption of failure for these parents violates 'common sense' principles of fairness and equity and disappoints the supposition that state services can be organised around these values.

Interestingly, in neither of these accounts is blame laid at the feet of individual workers. It is '*the local authority*' or '*the authorities*' who abrogate principles of fairness. Describing the forces of oppression in these impersonal terms highlights the difficulties and frustration of the workers who take a more critical stance towards assumptions of parental incompetence.

The following accounts elaborate the construct of the powerless worker trapped within oppressive systems.

Extract 9.xiii: John, advocate

1	J:	The particular social worker was really good
2	D:	Yeah
3	J:	But yeah she had she had no choice (.) she phoned up she said look I'm sorry
4		but I'm having to (.) you know I mean the social workers are so (1) um (.) you
5		know (1) they've got to be so careful about child protection issues
6	D:	Hmm
7	J:	Since the Climbie case
8	D:	Hmm
9	J:	It's no it's not any wonder (1) and um (.) you know um since the Children Act
10	D:	Yeah
11	J:	It's just everything is so (.) er
12	D:	So the fact that she'd had children removed meant that
13	J:	Yeah that she was considered to be [a a risky prospect
14	D:	[a danger
15	J:	To any other children
16	D:	Yeah
17	J:	So you know (.) she was never (.) she she you know (.) she was going to be
18		looked into

Extract 9.iv: Jane, children and families social worker

1	D:	I'm (.) sort of interested that from your perspective (.) it seems that (1) um (.)
2		Child Protection procedures are more:: (.) the norm than anything else with
3		parents with learning disabilities (1)
4	J:	Yeah

5	D:	Why do you think (.) why do you think that is (.) um (.) in this particular setting
6	J:	(2) Um (1) I think (1) maybe there are other women with learning disabilities
7		that we never hear about
8	D:	Hmm
9	J:	That aren't into (.) so they're not into Child Protection procedures
10	D:	Right
11	J:	(2) Um (1) sometimes (.) when it's come onto the ward like that (.) I think
12		everyone
13	D:	[Hmm
14	J:	[The ward staff's anxieties go sky high (.) and there's quite a pressure on (.)
15		because it's about having to make a very quick assessment before the woman
16		goes home
17	D:	Yeah it would be (.) wouldn't it (.) in a few days I guess (1)
18	J:	Yeah (1) and I suppose (1) you have to (.) err on the side of safety
19	D:	Hmm
20	J:	And that the procedures (.) we end up implementing them
21	D:	Yeah
22	J:	Because there is concern about (.) about (.) enough concern to actually say,
23		(.) well (1) we're not sure whether this child can go home or not [...] so I
24		suppose it is a safety first policy (.) really
25	D:	Hmm
26	J:	Which (.) um which might not feel right to the woman involved

This construction positions practitioners and clients as powerless, subject to inevitable processes that cannot be modified or delayed. John talks about the social worker having *'no choice'* (line 3) but to raise concerns about a mother having contact with other children, when her own children had been taken into care. Social workers have no room for manoeuvre, their only course of action is defensive and conservative (*'they've got to be so careful'* line 5). Similarly Jane says *'the procedures (.) we end up implementing them'* (line 19), suggesting that workers are passively caught up in administering 'procedures' that categorise some parents as 'safe' and others as 'risky'.

There is therefore an expected outcome (*'it's not any wonder'*, John, line 9) which allows no scope for other actions. The way that the workers are positioned in this construction severely restricts not only their range of action, but also their speaking rights within the discursive field as a whole. Though the social worker is described as 'good', presumably meaning sympathetic, engaged and seen as John as an ally, she is constrained to become a reluctant and apologetic agent of government policies and directives, such as the Laming report following the inquiry into the death of Victoria Climbie at the hands of her relatives. Equally Jane entertains the

possibility that following child protection procedures not only '*might not feel right to the woman involved*' (line 25), but might also be uncomfortable also to workers themselves, who '*err on the side of safety*' (line 17). Expressing uncertainty ('*we're not sure this child can go home or not*') will inexorably lead into discourses of assessment of risk and safety, where safety means taking action against the wishes of parents in order to eliminate any risks.

These narratives of social workers impelled to act defensively, even against their better judgements, acknowledge that practitioners are not happy with the overwhelming child protection orientation in social work practice. However, I suggest that 'following the procedures' positions not only children as vulnerable and in constant need of protection, but also practitioners themselves, in a contemporary social and political climate where they are constantly worried about their own vulnerability to criticism.

The construction of risk as professional jeopardy should be seen within the context of wider social constructions of child care work and workers, particularly social workers. These constructions reflect far-reaching shifts in the relationships between professionals and their clients, as well as between professionals, politicians and public opinion. In Section 2.3 I traced the social changes which have contributed to widespread understandings of child care practitioners either as 'naively hands-off' and therefore ignoring real risks to children, or as 'interventionist bullies' who over-react and needlessly break up families.

9.8 Concluding remarks: risk and individualization

In this final section I would like to evaluate the usefulness of Beck's and Giddens' theoretical constructions of 'Risk Society' in making sense of the professionals' talk that I have examined above. It is hard to deny that there is evidence here for a heightened level of awareness about risk when discussing children and family life. Although Beck and Giddens

emphasise the origins of contemporary risk anxiety in the public arena outside family life, in the uncertainties of the labour market, the lurking threats of environmental disaster, the unforeseeable nature of international political and economic trends brought about by globalisation, they also call attention to how such developments have destabilised traditional social configurations, including relations between men and women and experiences of family life.

In an oft-quoted passage, Beck explains our current preoccupation with children's welfare, and our cultural need to almost to sanctify parent-child relationships:

> *The child is the source of the last remaining, irrevocable, unchangeable primary relationship. Partners come and go. The child stays...The excessive affection for children, the 'staging of childhood' which is granted to them – the poor, overloved creatures – and the nasty struggle for children during and after divorce are some symptoms of this...The number of births is declining, but the importance of the child is rising* (Beck, 1992: 118. emphasis in the original).

This idea of the precious child links in with the protectionist and developmental discourses of childhood that I have discussed both in this chapter and the previous one. Understanding children in terms of their vulnerabilities and 'needs' means that special kinds of adult competencies and skills are required in order that children negotiate the vicissitudes of development to adulthood. The upbringing of the special, vulnerable child cannot be left to chance. Developmental and risk narratives weave together quite comfortably here with stages of development described as heralding their own particular dangers which parents must contain.

Whilst Beck appears to adopt a 'realist' orientation to risk, pointing to evidence for the multiplication of risks in contemporary society that generate 'risk anxiety', a Foucauldian approach (Culpitt, 1999) would be to link discourses of risk to the wider political project of the control of

individuals[2]: *'Expert institutions employ discourses of risk to filter information, deflect opposition and reinforce dominant norms'* (Mythen, 2004).

In this chapter I have indicated how participants use discourses of risk to advance particular constructions of parenting and childhood, and to reinforce norms around what is approvable parental and child behaviour. These discourses also reinforce norms of professional behaviour, and delineate what can be warranted as defensible behaviour in the professionals' accounts.

A key feature of 'Risk Society' reflected in my analysis is the way that risk and responsibility for risk has been individualised. Parents are accountable for protecting children from their own developmental vulnerability, from hazards in their everyday environment, and from their own unruly natures. There is little scope for a notion of shared responsibility for children at the level of the extended family, the local community or the state.

In part this individualisation of risk reflects the particular subjectivities which are nurtured in the risk society, namely autonomous, entrepreneurial selves (Giddens, 1991; Rose, 1996) who can quickly and flexibly respond to the rapid rate of social and economic change. However, contra Beck and Giddens, who propose that the growth of individualism has been matched by a reduction in coercive state power (Mythen, 2004), my analysis and other critiques (Hendrik, 2003) suggest the extension of state surveillance and intervention, especially for parents deemed deviant and irresponsible (Scourfield and Welsh, 2003).

Beck (1992) contends that the risk society has transformed attitudes to professional authority. Well-informed and self-regulating individuals are no longer dependent on experts to make up their minds for them, and are

[2] See the following chapter for a more detailed discussion of Foucault's concept of 'governmentality'.

in fact more likely to suspiciously view experts as fallible and driven by undeclared interests. There is certainly evidence in this chapter that professionals position themselves as vulnerable and exposed in circumstances where concerns about children are being raised. Discourses highlighting risk certainly seem to have particular implications for professional practice, making defensive, legalistic, conservative, short-term approaches and interventions more likely.

However, there is a contradiction here. On the one hand, professionals feel in the spotlight, vulnerable to criticisms as much relating to overstepping the mark as to negligence. They can no longer rely on deference to expertise, so that different relationships with clients have to be built, with the rhetoric of 'partnership' much to the fore. On the other hand, risk accounting and management have become key professional tasks with an emphasis on 'erring on the side of caution'. A not illogical response to this dilemma is to focus on distinguishing the 'high risk' family environments from the rest (Parton, 1998). The extract below suggests that workers make a distinction between parents who can be trusted to manage risks with regard to their children, for instance around the controversial area of immunisation, and deviant parents, such as those with parents with learning disabilities who lack the competence to do so.

Extract 9.xv: Carol, health visitor

1	C:	Because um, we cant (.) we can't impose that all parents must have their child
2		immunised this is what we hope to [achieve]
3	D:	[Hmm
4	C:	(.) At um the end of our um contact with clients but (.) um clients of social
5		class one and two refuse
6	D:	[Hmm]
7	C:	[and] nothing happens
8	D:	Right
9	C:	And I look at <u>that</u> um
10	D:	Right
12	C:	Comparison as well
13	D:	Hmm
14	C:	<u>They</u> refuse to have their child or children immunised
15	D:	Hmm
16	C:	And they quote all the [figures (.) and documents
17	D:	[Hmm
18	C:	Yeah, [yeah]
19	D:	[too::] and nobody um
20	C:	Nobody is going to make a fuss about [that]

21	D:	[They] aren't going to make a fuss
22	C:	about it (.)because (.)
23	D:	right
24	C:	clearly they are articulate, and can hold their corner (.) but u::m (2) on the
25		other hand the other scale of the spectrum is parents with learning difficulties
26		(.) you know
27	D:	Hmm
28	C:	a:[:nd
29	D:	[And they might get judged in a different way
30	C:	Yes
31	D:	for not [immun]ising their children
32	C:	[Yes] that's[right
33	D:	[they're seen as neglect[ful]
34	C:	[Poss]ibly (.) [possibly
35	D:	[Yeah

In the next chapter I look in more detail at ways in which professionals manage these sorts of dilemmas relating to authority, autonomy and control in their relationships with parents.

Chapter Ten: Professional Dilemmas

10.1. Introduction to Chapter Ten

In this chapter I focus on how the professionals positioned themselves and their clients as providers and recipients of services. When they talked to me as a researcher, the professionals were constructing narratives about their relationships with their clients. The complexities and contradictions within the accounts highlighted how the discursive economy relating to 'the caring professions' presented many seemingly insoluble dilemmas. What also becomes apparent is just how difficult to manage the professionals experienced their relationships with parents with learning disabilities as professional dilemmas became more acute and intractable.

First I review current debates about the nature of professional authority and power relationships between professionals and service users. In particular I contrast a Foucauldian perspective on professionals as agents of disciplinary power with views of disability activists and writers who, drawing from the social model of disability, have launched attacks on the 'caring professions'. I suggest that narratives of professional practice, which are often structured around dilemmas and conflicts between aspects of the professional role, can be seen to produce identities both for clients and professionals in a mutually constitutive fashion.

10.2. Professionals: altruistic public servants or oppressors?

Entering a profession often involves years of training, and induction into the culture and values of the professional group. Most professionals hold dear the sort of conceptualisation of their role outlined by Parsons (1968) and other functionalist sociologists, who characterised professionals as enacting institutionalised altruism and community values. From a philosophical perspective, Downie (1990) enumerated what he regarded were the idealised characteristics of a profession: skills and expertise; provision of a service to clients by means of a special relationship built on the professional's desire to help and 'sense of integrity'; authorisation by a institutional body and legitimation through public esteem (though the professional must be '*independent of the state or of commerce*', p.154); and a responsibility to speak out on matters of public policy and justice.

Whereas this view of professions assumes that, at least in an idealised form, professional status can position the worker at one remove from political agendas sanctioned by state power, proponents of the social model of disability take rather a different line. They view the 'caring professions' as one facet of the 'disabling environment' which throws up barriers against disabled people's full participation in society (Macfarlane, 1996; Swain and French, 2000). Professionals create dependency among disabled people first by controlling resources, acting as gatekeepers, and using legally authorised structures which make sure that they determine how services are administered (Oliver, 1990). Second, professionals limit the autonomy of disabled people by defining 'independence' in terms of the ability to undertake self-care tasks (washing, dressing, and mobility) rather than the ability to make decisions and be in control of one's life. From this perspective, *'...health care professionals have traditionally been seen to be 'oppressors' to disabled people* (Bricher, 2000: 781).

Third, welfare professionals have been represented as having a parasitic relationship with disabled people (Davis, 1994), actually fostering dependency in order to create a raison d'etre for the employment of middle-class social science graduates (Wolfensberger, 1989). Oliver (1990) argued that it is the professionals who are dependent on disabled people (rather than visa versa), for their jobs, salaries, status and sense of purpose. This state of affairs is not acknowledged by welfare systems. Pronouncements about aiming to provide support and promote disabled people's independence are a smokescreen:

> *There are always a few people somewhere who get habilitated into greater independence and competence, thus serving as a cover or front for the service supersystem* (Oliver and Barnes, 1998: .34)

This understanding of relationships between professionals and disabled people is based on stark dichotomies – oppressor/oppressed; powerful/powerless. It is drawn from juridical conceptions of power as something that the individual can possess in the form of fundamental rights which can be transferred or surrendered (Tremain, 2005).

Foucault (1965, 1973, 1977) described a more complex relationship between professionals and dominant forms of power. In his histories of social institutions developed to contain and control 'deviant' sectors of the population - the sick, the mad, the criminal – Foucault theorised a shift from **sovereign** to **disciplinary** power. Sovereign power, exercised by the state up until the Enlightenment, involved force, often enacted through public rituals and displays of authority, entailing subjection of the body[1]. Foucault saw the growth of modern, 'humane' institutions, for instance of medicine, education, and the penal system as accompanied by the rise of a different form of power

[1] The exercise of sovereign power is typified by Foucault in his reporting of the brutal execution of 'Damien the regicide' in the opening pages of Discipline and Punish (1977: 3-7).

which he characterised as 'gentle', pervasive and invisible; namely disciplinary power. This refers to the practices by which individuals are monitored, regulated and controlled through the exercise of 'regimes of truth' which delineate the 'normal' and the 'abnormal' and prescribe everyday 'micro-technologies' of surveillance, measurement and constraint. Moreover, contemporary authorities, whether political, medical, or legal require us to be constituted in particular ways and Foucault coined the term **governmentality** to express

> *the ensemble formed by the institutions, procedures, analyses and reflections, the calculations and tactics, that allow the exercise of this very specific albeit complex form of power which has population as its target* (Foucault, 1979: 20)

The professions which make up the psy-complex (Rose, 1989) including nursing, medicine, social work and psychology have a key role in governmentality and in promoting particular individual capacities according to specific forms of knowledge and in the furtherance of particular social goals (Rose 1996). I have already argued that the sorts of individual characteristics that are prioritised and promoted are those of autonomy, reflectiveness, independence and self-regulation. This analysis of the role of the 'caring professions' in governmentality has been applied to health visiting (Abbott and Sapsford, 1990; Peckover 2002), nursing (May, 1992; Cheek and Porter, 1997), social work (Chambon et al., 1999) and also specifically to the operation of learning disability services (Gillman et al., 1997; Gilbert, 2003).

An important aspect of Foucault's understanding of disciplinary power (since power is intrinsically linked with forms of understanding and objectification, he often used the term **power/knowledge**[2]) is that it is diffused and subtle. He used the metaphor of electricity to illustrate how power animates and

[2] See Allen (2005: 95). *'The virgule, or slash, in Foucault's neologism power/knowledge does not equate those two terms; rather it divides and distinguishes power from knowledge and then relates them back to each in a reciprocal economy in which they continually reproduce each other and sustain each other's authority'.*

constitutes social relationships and individual identities. Power/knowledge is not quantifiable; it is not exerted by the dominant over the dominated, or something that the oppressed can claim back in a zero-sum equation. Its actions and effects can be unexpected and paradoxical. Techniques of government which claim to be liberatory and participatory can be constraining and limiting, and perhaps even visa versa.[3]

I am interested in how these relationships of power are discursively constructed by professionals themselves. From a Social Model standpoint, for instance, we might expect that professionals use ways of talking about their work which position them as possessing confidence, status, and knowledge, whereas the client is seen as passive, dependent and needy.

I suggest that the constructs of 'the professional' are more complex than this sort of polarized description might imply, and encompasses a number of contradictions or 'dilemmas'[4]. In the words of Billig et al. (1988: 66):

> *Ideologically produced dilemmatic thinking arises when two valued themes of an ideology conflict, and these dilemmatic elements can spill over into a full-scale dilemma, when a choice has to be made.*

10.3. The 'Hunch-Shouldered Authority'

In their chapter on 'Expertise and Authority', Billig et al. reflect on the '*contemporary dilemma between authority and expertise*' (1988: . In an

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[3] I have already outlined some of the intrusive techniques of surveillance and homogenizing tendencies of Normalisation theory and practice. See also Gillman et al. (1997) and Gilbert (2003). Conversely, life histories of people with learning disabilities who spent many years in 'mental handicap' institutions suggest that within these oppressive regimes there were opportunities for residents to take on valued roles and to participate in clandestine sub-cultures (Atkinson et al., 2000).

[4] A dilemma can be defined as '*a situation in which one has to make a difficult choice between two courses of action, both perhaps equally undesirable*' (Longman Dictionary of Contemporary English).

authoritarian society, authority is unapologetically exercised by those possessing rank and status. Those on the higher rungs of the ladders expect deference and obedience from those lower down. However, in a modern democratic society, where every adult potentially may influence the future of the country through exercise of the right to vote, the view of each and every citizen should have equal weight. There is an emphasis on egalitarianism and participation reflected in and brought into being by the increasing democratisation of institutional discourses (Fairclough, 1996).

Yet, far from doing away with authoritative institutions, in modern society authorities have proliferated, in the guise of professionals and experts. Health and social care occupations such as nursing and social work, which were once seen as vocational, charitable, or imbued with public service values, have become increasingly professionalized. The expert's special skills are specified, examined, ratified and authorised by professional bodies. Respect for authority has survived and even thrives in the guise of deference to experts who are bound by codes of practice to behave in ways that command respect. However modern professionals cannot count on automatic deference from the recipients of their professional insights:

> *The expert is like a large individual caught up in a throng of smaller persons. The giant attempts to look inconspicuous by bending at the knees and hunching the shoulders. Trying hard not to step on tiny toes, the giant nevertheless tries to move the throng gently in the desired direction. One push too hard and the Lilliputians will turn in fury upon our Gulliver. One push too few and they will blame him for not sharing the vision provided by his extra height. The hunch-shouldered authority must proceed warily* (Billig et al 1988: 67).

According to this formulation, the dilemma for the expert/professional, who is constituted as superior to the recipients of her know-how, is how far overtly to exercise her authority without inadvertently provoking a rebellion in the ranks and therefore undermining her effectiveness.

10.4. Rebellious parents

Extract 10.i Liz, nurse specialist, child protection

1	L:	1) Often (.) I mean I'm thinking of a couple of families that I dea l:'ve worked with or
2		worked with the health visitor quite a lot (2) a::nd the health visitor's perception of (.)
3		the health visitor will identify that that that (.) these particular families have learning
4		difficulties(.) that the mothers particularly have (.) ss (3) in the um (.) not not
5		diagnosed probably(.) but in the (.) health visitor's estimation quite severe learning
6		diffic[ulties (1)
7	D:	[Hmm
8	L:	Um (1) but at the same time they are very hostile they are very aggressive=
9	D:	=Hmm=
10	L:	=They won't do what you [know
11	D:	[Hmm
12	L:	They won't follow suggestions (1) wha (.) things that the health visitor suggests they
13		won't follow advice proper[ly (1) and I think it is someti:mes (.) um the health visitor
14	D:	[Hmm
15	L:	Doesn't realise that perhaps (1) that that the parent is unable to (.) is unable to=
16	D:	Right right
17	L:	To follow that advice.
18	D:	Right (.) so it's not that they're:: (1) hostile=
19	L:	=No
20	D:	They are not really [understanding
21	L:	[but because their attitude is why haven't you done this, why
22		haven't you made up these feeds like I've said (1)
23	D:	Yeah
24	L:	Who do you think you are telling me what to do
25	DI	Ri::ght
26	L:	I can understand what you said the first time (.) you get into that sort of
27	D:	Yeah
28	L:	Conflict I think
29	D:	Yeah
30	L:	Which helps (.) nobody (.) umm:
31	D:	Yeah

Here Liz describes what happens when the professional Gulliver pushes the clients too hard. The client rebels. Liz dramatises this in lines 21 to 30 of Extract 10.i, adopting the voices of the hectoring health visitor and the recalcitrant client.

The health visitor's voice of authority is too strident and commanding; she expects her words to be translated into the parent's deeds. Liz suggests that this voice will elicit a hostile response from the client, who will experience it a challenge to her autonomy and status. In Liz's scenario, the professional has fallen into the trap of pulling rank, and asserting the superiority of her

expertise and knowledge. To imperiously repeated instructions Liz has the client respond as if the health visitor was drawing attention to the client's difficulties in understanding (*'I can understand what you said the first time'*, line 26).

These difficulties are presented as the reason why the interaction between the health visitor and the parent goes wrong in the first place. First, the nature of learning difficulties as a contestable label (there are not outward necessary and sufficient signs and symptoms) sets the scene for conflict between the health visitor and the mother, who since she has not been 'diagnosed' may not share the health visitor's formulation of her as having 'quite severe learning difficulties'.

Extract 10.ii: Liz, nurse specialist, child protection

1	L:	The(.) the client actually says no I'm not going to do that
2	D:	Hmm
3	L:	a::nd the health visitor gets very frustrated
4	D:	hmm
5	L:	because they don't know what else to do (.)
6	D:	[mm
7	L:	[really (.)
8	D:	how would you like things to be then (.) I mean if that if that's: the model that you
9		don't want to continue with,(1) what sort of model are you working towards
10	L:	(1) well I think we need a client-centred model don't we
11	D:	hmm
12	L:	We need to go in and we need to sit we need to try and encourage a perception in
13		those parents n try to get them to identify their needs.
14	D:	Hmm
15	L:	Because if they are not able to identify any needs (.) if they're not able to say(1) I can
16		cope with this or I can cope with that but I can't cope with this (.)
17	D:	Hmm hmm
18	L:	If we're not offering them help that they think that they need they're not going to take it
19		up are they (.)
20	D:	Yeah (1) and that sounds like also one of the difficulties at the moment, that it is quite
21		hard for some of the parents to identify their needs
22	L:	Yes
23	D:	They think they're they're
24	L:	That's right
25	D:	They're OK (1) And you're interfering.
26	L:	And we're saying no it's not OK and they're saying mind your own business (.)
27	D:	Is there any way round that do you think?
28	L:	Ha ha ((laughs)) (.) um (1) I think there has to be
29	D:	Yeah
30	L:	That's what we're trying to do
31	D:	Yeah

32	L:	We're trying to sort of look at different strategies to actually help (2) um (.) to empower
33		health visitors to actually empower their clients really
34	D:	Hmm [hmm
35	L:	[to try to (2)
36	D:	yeah
37	L:	find some way through really (2)

As Liz describes the situation, the authoritarian professional comes to a standstill, faced with the blanket refusal of the client to behave as expected. In reality, the authoritarian professional can take an even more coercive line of action, and invoke statutory child protection procedures that could lead to the removal of the child from the non-compliant parent. However, Liz instead turns to advocating a 'client-centred approach', which involves the 'empowerment' of the client.

It sounds as if a 'client-centred model' would mean that the client's views and goals would trump the authority and expertise of the professional. 'Empowerment', a term that Liz produces without any further explication, as if its meaning and worth were self-evident, presumably means that the professional hands power over to the client. The sort of individual constituted in this discourse is the more autonomous, self-motivating and 'self-steering' self (Rose 1989) of modern democratic society, in charge of its own destiny. It is also part of the agenda of the disability rights movement to claim this selfhood for disabled people, an aspiration that the government appears to wish to turn into a reality for people with learning disability with such documents as Valuing People (Department of Health, 2001). Has the 'hunch-shouldered authority' shrunk herself out of existence?

Oliver and Barnes (1998: 10) clearly thought not: *'Both state services and the voluntary sector have opportunistically responded to the challenge posed by disabled people's self-organisation by embracing the concept of empowerment'.*

Moreover, Oliver and Barnes have argued that state services undermine the self-organisation of disabled people by co-opting their agenda and claiming the empowerment of disabled clients as a central service goal. I think that this assertion can be supported through an analysis of Extract 10.ii.

Liz explains her solution to the problem where the client will not follow the professional's advice: 'We need to go in and we need to sit we need to try and encourage a perception in those parents n try to get them to identify their needs' (line 12-13). Just letting the parents do want they want is not going to be an option. After all, we assume that wants are based on individual, idiosyncratic and subjective 'desires' (Marks 1999) whereas needs can be objectively defined (Slater 1998) and are an expression of underlying deficits within the client. Usually the client's needs are assessed and defined by the professional, and this process is presented as a value-free, objective evaluation of the client. However, disability rights theorists (Barton and Clough, 1995; Oliver, 1990) challenge this discourse of needs and argue that the needs of disabled people are socially constructed, and reflect the impact of social organisation, power and ideology.

If professionals, following a 'client-centred' model allow clients to identify their own needs, will this mean that clients have more power and control? Well, not really. Because needs are constructed as self-evident and objective, the client can only identify what is already known to the professional. If the client's list of needs does not match the professional's (they think they are OK and you are interfering), there must be something wrong with the client – for instance, here they have learning difficulties. The way out of the impasse that Liz suggests is more 'empowerment' for the client. This suggests that she positions the powerless, downtrodden client as more likely to disagree with the health visitor's advice, perhaps because of resentment of the professional's elevated and powerful position. If the professional can even up

the power balance, the client will be more likely to listen to and adopt the professional's point of view.

Thus 'empowerment' becomes constructed as a strategy for deflecting conflict and encouraging compliance among clients, in other words, a form of professional practice (Baistow, 1995; Pease, 2002) deployed to manage the dilemmas of authoritarianism and choice in professional-client relationships.

> *The relative success of participatory approaches hinges not on reducing control, but on achieving a system of control that is more effective than other systems* (Barker, 1993: 433)

Extract 10.iii: Grace, learning disability social worker

1	G:	But I think it is also a great skill (.)
2	D:	Yeah
3	G:	It's a skill they need to develop (.) because no parent (.) nobody wants to be (.)
4		pushed
5	D:	Yeah=
6	G:	=Or have pressure on (.) so you've got to be ss skilled (.) you've got to be
7		diplomatic at the same time as (.)
8	D:	Hmm hmm
9	G:	You've got to respect people's (.) um views
10	D:	Hmm
11	G:	In terms of (.) their values (.) [and
12	D:	[Yeah
13	G:	And at the same time you've got to be able to (.) make them see the need (.) to to
14		change (.)
15	D:	Hmm
16	G:	And they have to have to feel that they're empowered
17	D:	Hmm
18	G:	Not (.) somebody forces (.)
19	D:	[Yuh
20	G:	[So that is why sometimes you would have conflict with parents if they feel that (.)
21		that you're pushing them

Grace describes professional practice relating to empowerment as requiring great skill (a point that she reinforces through repetition in lines 1, 3 and 5). This attribute is required to manage the central dilemma of how to convince clients to accept their own shortcomings and need to in change in line with professional conceptualisations (line 12) while avoiding conflict and communicating respect for the client's values. Her repetition of the phrase '*at*

the same time' (lines 6 and 12) gives the sense that the professional is juggling different agendas and considerations. Empowerment is here constructed as a *feeling* of self determination and self-efficacy. The skilled and diplomatic professional achieves the goal that parents experience themselves as in control, as if they have freely chosen to accept and alter their behaviour: '*And they have to have to feel that they're empowered*' (line 15)

So creating opportunities for empowerment of parents (or at least for them to feel empowered) can actually bolster and extend the professional's role. In the extract above, the professional is positioned as needing to develop more complex and sophisticated 'people management' skills. A similar point is made by Baistow:

> *Far from user empowerment limiting the intervention of professionals into the lives of citizens, in current empowerment discourses we see the space being created for new sorts of professional expertise to emerge and for new or transformed 'client groups' to be identified as the objects of this new type of professional attention* (Baistow 1995: 41).

10.5. The dependent client

Extract 10.iv: Beatrice, health visitor

1	B:	What you tend to find also is that you get overuse of the services.
2	D:	Right
3	B:	Er you know, and they become quite dependent on you (1).
4	D:	Mmm
5	B:	Um (2)
6	D:	Hmm
7	B:	I think there are advantages and disadvantages to that (.) um (.) because really (.) erm
8		the ultimate outcome for me is for them to be able to (1) for me to at the end of the day to
9		empower them in feeling respon (.) taking (.) er quite a lot of the responsibility for their
10		child
11	D:	Mmm
12	B:	And not necessarily waiting for me
13	D:	Mmm
14	B:	To say (.) yes we do need to do (.) [this or that
15	D:	[Right, right
	B:	But because of the difficulties (.) there's that there's that (1)degree of dependency

This passage illustrates further some of the complexities of the 'professional' discourse thrown up by the health visitor's contact with a parent who has learning disabilities and links in with the earlier arguments about the professionals' ambivalent relationship to power and control. Initially the idea of the dependent client is constructed quite negatively by Beatrice. A client who is dependent takes up an unreasonable amount of the professional's time, they '*overuse*' the service (line 1) and take more than their fair share. What is more, this sort of client works against the professional's *'ultimate outcome*' (line 8), and the goal of '*empowerment*' which is for the parent to '*take responsibility*' (line 9) for their child. The concept of parental responsibility is one that Beatrice elaborates at a later point in this interview. It seems to mean the ability (and obligation) parents have to make autonomous choices about their children and to act on these choices independently, without relying on input from professionals. .

Moreover, the dependent client, as well as avoiding the professional's attempts to be empowering, can also seen to be presenting risks, in terms of dangerous outcomes for the child. Wait passively for instructions from the health visitor may jeopardise the health and safety of children. Beatrice also paints a vivid and alarming picture of the sorts of medical emergencies children may face if their parents do not respond promptly to the first signs of illness:

Extract 10.v: Beatrice, Health Visitor

1	B:	They wait for you to make that contact, and then you discover that the child's been
2		unwell
3	D:	Right
4	B:	Um (1) yes (.) so there tend to be a bit of a delay in [seeking
5	D:	[hmm
6	B:	then recognising there is a problem (.) and knowing what to do (.) So consequently
7		children end up with probably long term upper respiratory tract infection
8	D:	Right
9	B:	Ear infection (.) they end up having them for quite a long time
10	D:	Hmm
11	B:	Which then of course leads to significant long term chronic problems:: hearing
12		problems (.) hearing loss

Beatrice goes to some lengths to emphasise the dangers of dependency, when it manifests as the parents' inability to take the initiative in dealing with their child's ill health. Serious health problems for the child will be '*probable*' (line 7), if not inevitable ('*of course*', line 11). She contrasts the shortness of the parents' delay ('*a bit of a delay*', line 4) with her repeated references to the chronicity of the child's consequent health problems (lines 7, 9, 11).

10.6 The interchangeable professional

Another disturbing aspect of dependency is that it suggests a close personal relationship between professionals and clients replicating aspects of a parent-child relationship. The dependent client stakes a special exclusive claim to the attention of the professional. In contrast to this, an ideal of modern professionalism is the interchangeability of the professional. Since all who possess a particular qualification have to undergo the same rigorous process of training and regulation, one professional is as good as another. Moreover, professionals are not on the whole rooted in particular communities or bound up in a network of local relationships; they move on from one job to another to further their careers. In many settings the term 'handover' is used to describe the process of reallocation of a client from one professional to another. This is a distancing term, since it suggests that the client is a parcel which can be passed from hand to hand.

Extract 10.vii: Liz, nurse specialist, child protection

1	L:	Well they will go in (.) when they meet a family they will make an assessment of the
2		family's needs
3	D:	Mmm
4	L:	Um (1) and if there is a family that they would consider to be vulnerable (.) and that's
5		the term that we use (1)
6	D:	Right
7	L:	Um (1) in relation to child protection they're actually identified then by being put in a
8		blue plastic envelope
9	D:	Oh right OK
10	L:	And put in the filing cabi[net
11	D:	[I see::
12	L:	So if a health visitor is knocked over by a bus tomorrow [and somebody else is is
13	D:	[yes

14	L:	coming to the filing cabinet, you immediately identify those families that need (1)
15		[perhaps that need perhaps
16	D:	[right
17	L:	immediate attention that need support.

Here Liz identifies the 'vulnerable' family with their bureaucratic existence as a set of case notes. The family are *'put in a blue plastic envelope ... and put in the filing cabinet'*. By this use of metonym the substitution of one health visitor for another can be seen as relatively unproblematic; families needing input can be identified *'immediately'*.

10.7 Another dilemma: closeness, control and 'boundaries'

Although the health visitors emphasise the importance of interchangeability of professionals in their language, the circumstances which require the replacement of their usual worker are recounted as unlikely, if not exceptional. Beatrice chooses the construction, *'if I happen to be away'* (line 21), suggesting the unlikelihood of this eventuality. Liz refers to exaggeratedly unlikely circumstances necessitating the replacement of a regular worker: 'if a health visitor is knocked over by a bus tomorrow' (line 12). These constructions might counteract any suspicions that health visitors leave their clients in the lurch, or that the professionals would foreground their own needs (to take sick leave or go on holiday or take another job) at the expense of their clients' needs.

Beatrice even suggests that there might be 'advantages' to having dependent clients, but does not spell out what they are. Maybe she would be on dangerous ground to assert that there are benefits to the professional when the client is compliant and uncritical. When Beatrice does talk about the difficulties associated with clients who are too 'dependent' she makes it clear that she personally is not hampered by their demands on her time *('And I don't see that as a as a hindrance for me'*, line 19). Similarly, Sue disavows

the idea that she might find her client's demands beyond her capacity to deal with them

Extract 10.viii: Sue, health visitor

1	D:	Do you think that things have changed(.) do you think that your role has changed as
2		you've got to know her (.) um as you've become more involved
3	S:	(1) I think so (.) I think (4) yes (.) she's she (4) oh how can I say it (3) she's become in
4		a way more demanding in in her way since (.)
5	D:	She's asked more of you
6	S:	Yes (.) yes in various ways
7	D:	How does that feel (.) for you
8	S:	Well (.) I don't mind too much (.) I (.) because I know her quite well
9	D:	Hmm
10	S:	The demands aren't sort of out of this world or anything so I can cope for the moment
11	D:	Right

Noticeable in this extract are the number of pauses, hesitations and repetitions in lines 3 and 4, leading up to Sue's description of the mother, her client as *'more demanding'*. A listener would be aware that this is a difficult topic and would pick up Sue's hesitancy in labelling her client *'demanding'*. Sue then makes it clear that the client's demands are manageable, and she feels able to respond to them, *'for the moment'* (line 10). We might pause here to consider what effect Sue is aiming for by fending off the idea that her client's demands are overwhelming, and beyond what Sue could be expected to cope with. She seems to be referencing a 'Florence Nightingale' sort of professional who is selfless, available and uncomplaining, in contrast to the limited, conditional availability of the interchangeable professional. May (1992: 593) has proposed that this aspect of professional identity continues to have resonance, as the payoff in terms of personal satisfaction in situations where a substantial part of the professional's work is unvarying and predetermined:

> *Routine, task allocated work organisation in nursing has always relied on nurses being given a sense of personal value and moral worth through the inculcation of an ideology of selfless devotion to duty.*

Sue suggests that the client's demands are manageable because they occur in the context of a relationship, 'because I know her quite well' (line 8). The relationship is the conduit through which the professional's work is done.

Extract 10. ix: Sue, health visitor

1	S:	Yes and I think that you could say that the um relationship that I've got with
2		Samantha is actually very very good
3	D:	Hmm
4	S:	And she does trust me (.) and she does come down
5	D:	Hmm
6	S:	And I think that's good and I wouldn't like her not to have that opportunity of not
7		coming down (1) yuh (.)

In Sue's view, the quality of her relationship with Samantha, and the trust between them, means that Samantha will come and see Sue, and allow professional work to take place. In contrast to the Interchangeable Professional, this construction of the professional talks about relationships, trust and closeness with clients as prerequisites for work to take place. In this formulation, the professional who adheres to an impersonal, distant authority simply would not achieve anything. However there is an overall goal for the professional's interactions with the parent, her attention to building up trust and creating space for the parent to access her when necessary. This is to ensure that the professional can undertake her job of monitoring the family and shaping the client into normalized parenting behaviours.

Extract 10.x: Beatrice, health visitor

1	D:	Because even though they might need the input um (.) but how do you then
2		encourage them to do more for themselves
3	B:	Yes
4	D:	How do you cope with that
5	B:	Well I think that it boils down to support (1) and er (1) um (.) increasing the number
6		of contacts with clients
7	D:	Right
8	B:	And you start to (1)
9	D:	[Hmm
10	B:	[And at the end of each contact, always make another date for contact (1) so:: (1)
11		that they know when your next (.) you know
12	D:	Yeah
13	B:	When the next point of contact is going to be

Beatrice tells me about the importance of convincing parents of her reliability and building up a relationship of trust. Rather paradoxically this strategy is mentioned in the context of me asking her how she works towards achieving the goal she has mentioned before, namely that of encouraging autonomy and responsibility among parents. Maybe she assumes that only by making herself accessible to parents and convincing parents of her willingness to support them, as well as maximising opportunities for monitoring and guidance, will they turn into the independent 'empowered' parents that she hopes.

10.8 The role of advocate

The participants most likely to position themselves as holding back from the exercise of professional authority over parents, were the advocates. The role of the advocate for people with learning disabilities varies widely across different organisations and contexts (Atkinson, 1999). Core aspects of the role involve supporting people to get their voices heard and to negotiate with service systems in line with the disabled person's own agenda and aspirations. Valuing People locates advocates as a key element in realising the stated goal of increasing choice, independence and participation of learning disabled people.

> *Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices. Advocacy helps people put forward their views and play an active part in planning and designing services which are responsive to their needs* (Department of Health, 2001: 46).

However, the role of advocate can extend further. Booth and Booth (1999) described seventeen different functions for advocates, including, voice, interpreter and sleuth. Naming functions such as witness, mentor and confidante and stressing the frequency and informality of their contacts with parents suggest an expectation that advocates establish close personal

relationships with clients with an eradication of power imbalances between the advocate and parent as the ideal (Booth and Booth, 1999).

However, positioning themselves as close and non-directive personal supports to parents can bring about problems for advocates, as the following extracts suggest.

Extract 10.xi: John, advocate

1	D:	What why do you think that is potentially difficult
2	J:	Well you know (.) in terms of her vulnerability in terms of working females
3	D:	Yeah
4	J:	I mean I always that if the advocate's a male (.) that's an issue
5	D:	Right
6	J:	When you are working with learning disabilities
7	D:	Right
8	J:	So er I think you have to be aware of that (.) and I think um
9	D:	That she might have a kind of particular kind of attachment to you
10	J:	I think that (.) that could be an issue
11	D:	Hmm
12	J:	Especially if I was being a pseudo counsellor
13	D:	Hmm
14	J:	So I think I had to be aware of that
15	D:	Hmm
16	J:	I was careful that there wasn't that sort of thing building (.) so whilst that
17		sometimes she needed my support I it wasn't that she was drawing on me you
18		know as a means of supporting her emotional
19	D:	Hmm
20	J:	Needs (.) which she needed (.) and er
21	D:	Hmm
22	J:	that was quite difficult as I say I needed to be careful of that

John talks about the risks to client and advocate that can accrue from close and supportive relationships. His use of the terms '*female*' (line 2) and '*male*' (line 4) are equalising in that they reduce the advocate and the mother in the same way to their physical, gendered identities. However, introducing the idea of physical attraction puts John in the dangerous position of potential sexual abuser (the mother is '*vulnerable*', line 2). He is happy to provide support in general terms, but not to get involved in '*supporting her emotional needs*' (lines 18-20) with the intimacy that suggests. That would put him into the role of '*pseudo counsellor*' (line 12), presumably someone who engages in therapeutic emotional work with a client without the skills to do so, and

perhaps for their own gratification to boot. John's dilemma is how to manage relationships of closeness and trust, part of his remit as an advocate, without 'overstepping the mark'.

Extract 10.xii: Rachel, advocate

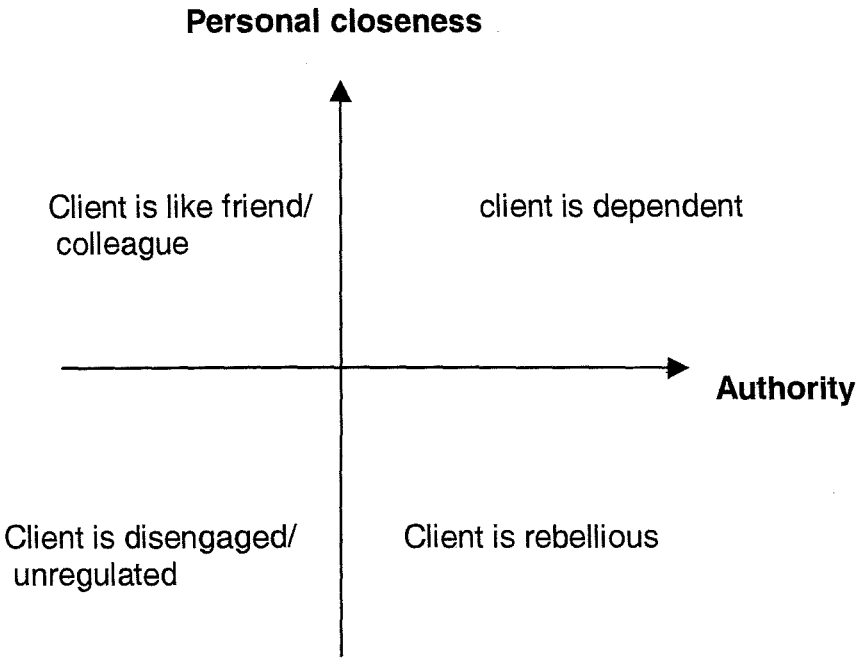
1	R:	It's not for me to push her into doing something it's to make [sure
2	D:	[hmm
3	R:	She's got the information she [needs
4	D:	[hmm hmm
5	R:	And then watching someone make the wrong decisions (.) and you know
6	D:	Hmm
7	R:	You think oh no
8	D:	Hmm
9	R:	But as an advocate you have to be really careful that you're <u>not</u> putting your views
10	D:	um
11	R:	Hmm
12	D:	And what <u>you</u> think should be happening
13	R:	Hmm
14	D:	(.) or pushing someone in that direction
15	R:	Ye[ah
16		[and that sometimes can be difficult especially when (.) you know the questions
17	D:	are you know is this person managing in bringing up a baby.
18	R:	Yeah
19		You know, there have been occasions where I have felt actually oh my god (.) you
20	D:	know
21	R:	Yeah=
22	D:	=This is worrying me
23	R:	Hmm
24	D:	But it's quite difficult to be in that place
25	R:	Hmm
26	D:	And you have to think quite carefully
27	R:	[Hmm
		[I think that's where supervision is really important

As an advocate Rachel seems to position herself in this extract at a fair remove from the parent with learning disability. She proffers information, she watches, she takes care to be 'non-directive', neither 'pushing' the parent to act in a particular way nor bringing her own views to the forefront. Her expressions of dismay ('*oh no*', line 7; '*oh my god*', line 18) locate her as a rather powerless bystander. She describes her dilemma as having the expert understanding that the parent's decisions are '*wrong*' (line 5) and '*worrying*' (line 21), but having to watch the consequences of these decisions unfold without imposing her own views.

In both these extracts, the advocates seem to be stressing their own vulnerabilities and feelings of awkwardness and confusion. Does this mean that they are relinquishing professional authority altogether? What might be happening is that they are constructing themselves as a different kind of skilled professional, one who is thoughtful, aware and reflexive. These are the aspects of the new sort of professional expertise that Baistow (1995) suggested were called forth by discourses of client empowerment (see Section 10.4). John and Rachel are doing 'being empowering experts' by repeatedly drawing attention to their thoughtful *awareness* of complexities (*'I think you have to be aware of that...So I think I had to be aware of that'*; lines 8 and 14 in extract 10.x) and their consideration and carefulness (*'I was careful...I needed to be careful of that'*, lines 16 and 18 in extract 10.x; *'And you have to think quite carefully'*, line 25 in extract 10.xi). Rachel also mentions her use of supervision, which she describes as *'really important'* (line 27); effective use of supervision being one mark of the reflexive, self-aware and self-monitoring professional.

10.9 Conclusions

In this chapter I have attempted to 'deconstruct' the concept of the professional and reveal the complex and sometimes contradictory opportunities for action that this concept offers. The professionals position themselves at various points along the dimensions of authoritarianism and personal closeness to their clients (see diagram below)



In this schema, the professional's orientation to the dimensions of authority and personal closeness to their clients opens up different positions for their clients to occupy. I have tried to illustrate how the various client 'slots' present dilemmas for the professionals in how best to achieve the aims of the agencies they work for. In fact, all the client slots on the diagram above create difficulties for the professional as I have argued in the analysis of the accounts above.

Moreover, for the professionals, the factor of the parent's learning disabilities can be discursively employed as getting in the way of a satisfactory client-professional relationship, with the learning disabled parent falling short of the autonomous, 'empowered' client. What also seems apparent is that the enactment of the professional role in contemporary service systems is structured around contradictions and dilemmas. From this perspective, the analysis does not seem to support the expectation from a 'social model of disability' perspective on the way that professionals construct their

relationships with clients, described in the beginning in this chapter. The analysis suggests that professionals' construction of their role is complex and dynamic, containing dilemmas and paradoxes. The analysis also points towards another insight, that within discourses, subject positions are mutually constitutive. Delineating a position as a certain kind of professional creates a space for a certain kind of client. There is a point of contact here with the work of Jarman et al. (2002: 556) and their investigation into 'political subjectivity', examining

> *...the ways in which social institutions (families, schools, prisons, militaries, economies, professions, disciplines, languages, narratives and fields of knowledge) and those 'subject' to them enter into a relationship with them (willingly or not) produce each other as comprehensible.*

As I have argued earlier in this chapter, according to a Foucauldian understanding, power is conceptualised not just as something that an agent in authority owns or possesses, and uses in a unilateral way to coerce the powerless. Power (or what he calls 'power/knowledge) flows through and animates discursive practices. Both the professionals and their clients are discursively created through the way that power/knowledge potentiates the positions they can occupy. Whereas Foucault's formulation has been criticised for seeming static and impervious to change, what seems to be happening in these transcripts is an ongoing process of shifting and accommodation (involving reflexivity around their own use of discourse) on the part of the professionals to find positions for themselves and their clients to occupy in order to adapt to the intrinsic dilemmas of their situation.

I have argued that the above conceptualisation of the relationship between power, language and practice with its emphasis on disciplinary power and governmentality, may inform the process of professionals' interactions with parents with learning disabilities. However, reflection on some of the research reviewed in the literature review (particularly relating to the rates of

removal of children from these parents: see Section 3.5.1) and my own clinical experience reminds us there are times when the state does not hold back from the forceful exercise of sovereign power. As Allen (2003) has argued, even though the exercise of disciplinary welfare power has become more subtle and pervasive the state does not hold back from coercion, exclusion, and in the case of parents with learning disabilities, the forced removal of children, when professionals feel that their objectives can not be met by other means.

Chapter Eleven: Professional and Personal Identities: Identification and Resistance

11.1 Introduction to Chapter Eleven

In the previous chapter I examined the relationship between professionals and parents with learning disabilities in terms of the dilemmas thrown up by their professional status and activities. My assumption was that professionals aim to achieve the goals of their organisations, creating the 'right kind of clients' who are self-regulating and self-managing, but always in the direction of meeting 'needs' defined by the professionals themselves. Although I have been critical of the Social Model conceptualisation of professionals as always overtly authoritarian and controlling, I do tacitly endorse the idea that professionals are essentially involved in exerting normalising control over parents with learning disabilities, despite facing sometimes intractable dilemmas. I point out how such dilemmas arise as an adjunct of the professional's position within modern democratic societies where there is considerable ambivalence about investing professionals with authority over and control of self-determining citizens.

In this chapter I examine the relationship between the professionals whom I have interviewed and the wider organisational systems in which they work and the professional role itself. I contend that professionals themselves are subject to disciplinary control by means of their

relationship with the organisational context. This control may be perceived as part of what Stronach et al. (2002) term '**economies of performance**'; the set of interpretative repertoires, stated values and discursive practices associated with what has come to be known by the shorthand term of 'audit culture' (Strathern, 2000) or 'managerialism'[1]. Being situated in relation to 'economies of performance' means referencing professional activities in terms of quantitative measurements such as 'quality indicators', 'cost-effectiveness' or 'outcomes'. In contemporary service settings professionals are required to not only to submit to the 'audit culture' with its emphasis on 'value for money', but also to propagate it through self-management and management of others. Stronach et al. (2002) suggest that an alternative set of discursive resources available to professionals relate to '**ecologies of practice**':

> *The accumulation of individual and collective experiences of teaching or nursing through which people are led to being 'professional' – personal experiences in the classroom/clinic/ward, commonly held staff beliefs and institutional policies based on these, commitments to 'child-centred' or 'care-centred' ideologies, convictions about what constituted 'good practice' and so on* (Stronach et al, 2002: 122).

Recent research on professionals working in a variety of settings has examined professionals' orientation to these two spheres of influence, often with an emphasis on the conflicts and contradictions between them. For instance, in Sturm (2004) and Syrett et al. (1997) practitioners draw attention to the gap between what they expect of themselves as caring, concerned and competent professionals who base their practice on personal involvement with clients, and what they actually achieve in practice in a climate of restrictive financial management. In this literature managerial and professional cultures are constructed as locked in battle, with professionals struggling against repressive practices: '*there is an*

[1] Syrett et al (1997: 159) offer the following definition:

> *'The term 'managerialism' denotes nothing more than a system of organisational and budgetary control directed at the most efficient and effective use of resources'*

image of practitioners as heroic pirates resourcefully bending the rules' (Brown and Crawford, 2003: 68).

However, another perspective might suggest that professional identities are more complex and even accommodating to elements of the 'economies of performance'. Commentators have pointed to the blurring of the boundaries between professionalism and managerialism (Brown and Crawford, 2003; Dent and Whitehead, 2002) and provided examples of managerialist discourse being integrated, with various degrees of enthusiasm into professional self-understandings (Stronach et al., 2002; Dent and Whitehead, 2002).

In this chapter, I look at how my participants orientate themselves towards 'economies of performance' and 'ecologies of practice'. I examine the sorts of conceptualisations of 'learning disabilities', 'parenting' and 'professional identity' that become salient in this process. In Chapter One I explained my justification for looking at professionals' talk: it is the professionals who enact and reproduce constructions of parents with learning disabilities informed by the legislative and policy framework. Can we also see professionals as agents for more progressive change, who challenge and resist oppressive practices against these parents, and challenge discrimination? What are the possibilities for collaboration and alliances between professionals and parents as evidenced by the data in this study? My starting points here are my own professional experiences as a clinical psychologist working with people with learning disabilities, my analysis of how the organisational context facilitates or constrains my work.

I work in a multi-disciplinary community team where there seems to be a lot of room for questioning and sometimes heated debate. Opportunities for challenging what we see as our own and others retrogressive attitudes and our own organisational policies and priorities arise in team meetings, supervision sessions and informal meetings in each other's rooms and in the team kitchen. None of us would be happy to think that we were

colluding in objectifying practices with relation to parents with learning disabilities which limit their life opportunities and reinforce patterns of family of life which disempower children and deskill their parents. From the discourse analysis point of view the question is how it comes about that we feel we are doing our best to help and support these parents?. What are the organisational relationships and discursive practices which construct us as professionals? What are the implications of accepting these? Conversely, can we recognise these and resist them?

So far I have identified the way that parents with learning disabilities have been constructed within discourses highlighting their deficiencies as autonomous, thinking subjects, as parents and as 'clients'. In this chapter I examine possibilities for different conceptualisations which arise when professionals talk about their relationships to the organisational context. I have already suggested that service settings confront professionals with dilemmas and contradictions between externally imposed 'economies of performance' and the 'ecologies of practice' which are part of their professional identities.. What are the implications for professional subjectivities in these service contexts; first as constrained by structural factors over which they have little control; second as agents in narratives of resistance and rebellion; third as connected with parents with learning disabilities, through common life experiences and as potential targets of the same sort of surveillance and condemnation that these parents themselves experience; and fourth as witnesses to competence and skill exhibited by these parents?

11.2 Structural constraints

It is almost axiomatic of public services that they are seen as falling short of demands placed on them. A managerialist discourse links this falling short to excessive bureaucracy and general inefficiency, and though these criticisms are more often directed at those who control and direct services practitioners themselves are not immune to imputations of

mismanagement of time and resources. Instead of seeing tighter financial control and cost-cutting as the way to ensure better services, an alternative discourse draws attention to the general climate of restriction and lack of investment in public services as responsible for exacerbating health and social inequalities.

In Chapter Ten I explored how some of the responsibility for the failure of parents with learning disabilities to be adequately and satisfyingly 'empowered' by professionals was constructed as resulting from a lack in the parents themselves; either a failure of understanding or a failure to 'take responsibility'. An alternative construction draws attention to the lack of resources that are available to support effective work with these parents.

Extract 11.i Brian, children and families social worker

1	B:	Well (1) I don't think we are very good at providing ((...)) intensive
2	D:	Hmm
3	B:	Like this office (.) it (.) that covers quite a wide area
4	D:	Right
5	B:	It's extremely busy (.) it's got two family support workers who (.)work nine to
6		five (.) Monday to Friday (.) so (.) they they [don't provide
7	D:	[Two (1) that's for all the families
8		that you work with
9	B:	Yeah (.)and a lot of them do need (.) a lot of them (.) you know=
10	D:	=Yeah
11	B:	The kids have got (.) practical problems which then (2) we don't sort out (.) so
12		things get worse (.)
13	D:	[Right
14	B:	[For everybody
15	D:	Hmm
16	B:	But (.) I think the worse thing for people with learning difficulties is that because
17		we are losing resources like nursery support services
18	D:	Yeah
19	B:	And child-minders (.) family support and all the rest of it (.) then (1) for families
20		who do need that bit of practical support
21	D:	Right
22	B:	Or advice from time to time (.) they are not getting it (1) which is going to make
23		things worse for the children

Brian uses **minimization** (Potter, 1996), a rhetorical device which emphasises the limited size, nature and significance of a phenomenon to underline the unreasonableness of failing to respond to families' needs because of the reduction in available resources in his department. Families do not require a great deal of input, just *'that bit of practical*

support' (line 20). Sometimes not even practical support is necessary, just *'advice from time to time'* (line 22).

Brian uses the familiar idea of 'a stitch in time saves nine' (line 11-12 *'The kids have got (.) practical problems which then (2) we don't sort out (.) so things get worse'*) to introduce the idea that although the present difficulties are hardly overwhelming, they may become so if action is not taken. His use of the *'then...so'* construction draws attention to the inevitability of a negative outcome when problems are allowed to get out of control. Therefore the action orientation of this passage is to blame the escalation of problems on the loss of resources. The implication is that if Brian himself was given more control over the sensible disposal of resources, potential crises would be averted.

11.3 Time and the busy professional

Remembering the argumentative structure of discourse, at this stage we might wonder what are the counter-arguments that Brian might be trying to anticipate or rebut in this passage. Logically, we might expect the reverse argument to be that the needs of parents with learning disabilities and their families are indeed inexhaustible and overwhelming for professionals. In the following extract, John talks about his decision to end his involvement with a mother whose life experiences during the time John was working with her included homelessness, rape, removal of her children, conflict with her family, and domestic violence.

Extract 11.ii John, advocate

1	J:	(.) Er::m and just thinking (.) you know right this can't just go on and on it's time to
2		call a call a halt really
3	D:	Yeah
4	J:	In terms of the actual time aspect (.) how many hours I was spending
5	D:	Hmm
6	J:	Phoning round (.) attending meetings
7	D:	Hmm
8	J:	Huge
9	D:	Really
10	J:	And it's not my job (.) I'm not funded to do it

In this construction, parents with learning disabilities seem to raise the possibility of limitless need for service providers; not only because their children will need support for many years, but also because of the disadvantage and social exclusion that they experience, their lives are beset by constant crises, that professionals feel they must tackle. John argues that need on this scale seems to threaten 'professional boundaries', structural limitations enforced by job definitions and funding specifications.

John speaks with sadness and frustration of his inability to continue to support a mother whose life has been marked by abuse and loss. In the next extract, Leanne talks about parents at a family centre, who are not immediately faced with such severe and damaging crises, but who also are faced with limitations to the support they receive because of organisational constraints:

Extract 11.iii Leanne, manager of residential family centre

1	L:	Because their learning (.) their ability to learn is much slower
2	D:	Yeah
3	L:	And they need more repetition of (.) of ways of doing things (.) and particularly if
4		they don't have literacy skills that (.) [it (.) three
5	D:	[Hmm
6	L:	months is just no way

Leanne is drawing attention to the parents' slow rate of learning to argue for greater flexibility in the length of contract that various local authority social services are prepared to pay for. What Leanne identifies as the instrinsic slowness of learning disabilities requires a longer service response. Parents with learning disabilities do not fit into the usual way of doing things or the timescales which that have been predetermined, often by budgetary considerations.

Similarly, Kate and Jill both argue that people with learning disabilities need to be given more time so they can have a chance to understand

what is going on; what the service expectations are; and in order to be supported to change.

Extract 11.iv Kate, counselling psychologist

1	K:	Um (2) child protection conferences are difficult
2	D:	Hmm
3	K:	Because I don't think (1) there are different agendas for everybody (.) and um
4		(1) [I don't think
5	D:	[Right
6	K:	They take into consideration the individual interests for everybody (.) which of
7		course is difficult
8	D:	Yeah
9	K:	(1) I don't think (.) they are geared towards an understanding of someone who
10		has a learning disability to take the time [to explain
11	D:	[Right
12	K:	to them what's going on
13	D:	Hmm
14	K:	To give them a chance to say what they want to say

Extract 11.v Jill, hospital social worker

1	J:	But I didn't have the time (.) um to work with her in the way that I would have
2		liked to have done
3	D:	Right
4	J:	And I don' t think things were explained to her as thoroughly (2) [Things were
5	D:	[Hmm
6	J:	explained to her
7	D:	Right
8	J:	But I knew she wasn't taking enough of it in
9	D:	Hmm hmm
10	J:	But I didn't have the (.) the <u>time</u> to do that properly
11	D:	Hmm
12	J:	Because we got four days to do this assessment and um (.) I got all the other
13		things that I was supposed to be doing at the same time
14	D:	Yeah
15	J:	And to try and fit that in was really <u>really</u> difficult
16	D:	Sure
17	J:	But it felt (.) it didn't feel right (.) um (1) it felt uncomfortable

Whereas the constructions of people with learning disabilities as dissembling, acquiescent or naïve which I discussed in Chapter Six, are in overall terms 'deficit discourses' where the problem or lack of skill resides within the person with the disability, this way of talking has a relational framework. The objects in the discourse are the parents with learning disabilities, the professionals who are telling their stories and external forces, which undermine or constrain the work that the professional is trying to do. The relevant aspects of the work context are not directly named. Kate mentions '*different agendas*' (line 3) operating from outside

the immediate context, and Jill explains '*we got four days to do this assessment and um (.) I got all the other things that I was supposed to be doing at the same time*' (lines 13-15) referring to time parameters and other duties that are beyond her control.[2]

When professionals have to account for their activities in terms of outcomes and results (for example professional activities linked to government league tables 'best value' reviews, performance management and clinical activity statistics), 'time' becomes a rare commodity – and an expensive one. An emphasis on 'efficient' and 'effective' use of staff time, as well as 'value for money' and cost-effectiveness' is part of the 'corporatist/managerialist' discourse' which has come to dominate the way that welfare organisations present themselves (Rapley and Ridgway, 1998). Instead of a ideal of 'care' based on a process of 'getting to know you' and enacted through personal interaction as part of an ongoing relationship, professionals are expected to assemble and administer 'care packages' whereby 'care' becomes a commodity to be delivered in a cost-effective and routinised way (Rapley, 2003). Whereas the rhetoric of the corporatist social care discourse highlights the individual choices and options available to those who 'consume' services, a depersonalised, routinised and market-led 'service delivery' system militates against an individual service user having a service geared to her individual pace and priorities.

Both Carol and Jill position themselves as 'uncomfortable' with or finding 'difficult' the priorities of the service agency they work for which can

[2] Wodak (1997: 194) talks about 'the myth of time' which operates in an outpatient ward. This is one of the 'myths' which she contends exist to cover up and hide internal contradictions and conflicts between different demands and roles experienced by staff. These myths not only mask contradictions, but also function to bolster the authority of the staff present:

> *this overburden and the constant pressure of time for the members of the outpatient ward have the function of proving the meaning and necessity of the action.*

In fact, she shows that a great deal of time is wasted, for instance waiting for a senior doctor to appear to make an executive decision.

enforce its own 'agenda' or time schedules. In suggesting that this system is unfair, they ally themselves with a different model of care, based on understandings of individuals through time-consuming relationships. From the perspective of an 'ecology of practice' which provides reference points for '*good practice*', Jill articulates a sense of falling short (line 1), of being '*uncomfortable*' (line 17). Both she and Kate present themselves as understanding what parents with learning disabilities require in terms of time to comprehend what is going on, but frustrated in their incapacity to demonstrate their knowledge and skill. However, despite their discomfort, both Kate and Jill present themselves as caught up in the service time priorities imposed by nameless 'others'. The parent is therefore the victim of the system (not of the individual workers) which demands speed and efficiency in processing clients. In the following section I examine an account where a story of resistance to what are constructed as externally enforced 'economies of performance' is recounted.

11.4 A narrative of resistance

Extract 11.vi Vicky, hospital social worker

1	V:	(2) There's a case that I'm thinking about that is in my mind (.) that is always
2		(1) um (2) sort of (1)
3	D:	Hmm
4	V:	I've always felt (.) very unhappy about (.) what happened
5	D:	Yeah
6	V:	And I'm just trying to think of what you've (2) I suppose (.) it's a bit of a
7		resource question (1) because (.) what I thought with this couple [was that
8	D:	[Hmm
9	V:	They didn't get the (.) support they <u>needed</u> (.) in that they weren't offered (1)
10		the residential mother and baby or whatever was: not an option
11	D:	Right
12	V:	It was actually a previous student of mine who worked with this couple
13	D:	Okay
14	V:	The woman had learning difficulties (.) the father didn't (1) [...] my student and
15		I tried to work with her (.) antenatally and we did the Conference report
16	D:	Hmm
17	V:	Now I was told bb (.) before we went to the Conference (.) that residential was
18		not an option and I shouldn't be recommending it
19	D:	For any particular (.) reason
20	V:	To do with <u>money</u>
21	D:	Do (.) did you feel that that would have been the best option
22	V:	Yes (1) yeah If she would have taken it
23	D:	Right
24	V:	I mean (.) I felt that the woman in the end had to chose between her partner
25		and the baby and she chose the partner (1) and (.) the partner (.) when they

26		went home (.) wh (.)
27	D:	[Yeah
28	V:	[What (.) happened was they went home with a package (.) not a very (.) um
29		not a very (.) good package I didn't think (.) a rather inadequate package
30	D:	Hmm
31	V:	(.) I thought it was very risky for the baby but (.) I also felt that it wasn't what
32		they nee:ded (.) I felt that woman needed the same (.) [um
33	D:	[Hmm
34	V:	If they were on their own (.) maybe they (.) wouldn't have gone into the
35		mother and baby without the partner (.) or (.) or maybe they wouldn't have
36		agreed to go into residential (.) um (1) but (.) they weren't told
37	D:	Right
38	V:	And very quickly he got (.) and he got (.) hit (1) and very quickly the baby went
39		into care (.) and the baby's in care now (.) and is up for adoption as far as I
40		know
41	D:	Right
42	V:	And (.) it always feels (1) I mean (.) I didn't (.) I remember my student (.) I said
43		(.) well put it down as an option (.) we're not just going to pretend that it
44		doesn't exist (1) and I remember at the Conference (.) she put that down as
45		the first option and the Chair of the Conference looked at the manager who
46		was there (.) and said is (.) is that an option
47	D:	Hmm
48	V:	And she said no (2) so what we're looking at there we are looking at going
49		home with a package of care (.) and that (.) I was (.) that (.) I think that is just
50		appalling (1)
51	D:	Presumably that is an option for some mothers
52	V:	[Yeah
53	D:	[Do you know why (.) it wasn't an option for this one (.) and (.) whereas it
54		might have been held out as an option for others
55	V:	It was at a time when there was almost like a (.) blanket ban on residential (.)
56	D:	[Right
57	V:	[It was a time when the money was really really short (.) towards the end of
		the financial year

Vicky told me this story right at the end of our interview, after I had gone through all of my questions and was about to wind up the interview by asking '*is there anything else you want to talk about that I haven't asked about so far*'? The timing of her narration and her description of the case as one that has stuck in her mind because she was unhappy about the outcome makes it clear that this is a 'troubling' case; which encroached on sensitive ethical and professional issues.

Vicky presents herself as an expert who is able to assess and determine the parents' 'needs'. I have already discussed the rhetorical power of employing 'needs language' in Chapter Ten, and the way that 'needs' are assumed to be objective and self-evident. In this passage, Vicky uses a reference to the disabled mother's needs to warrant her criticism of services, rather than of the mother herself. Using the discourse of needs

creates what Marks (1999) calls an 'emotional imperative', in the sense that it mobilises a left/liberal welfare discourse within which identified 'need' is linked to entitlement. Once needs have been defined, then the requirement is for services to address them.

In this passage the role of the professional is to recommend the best way that the disabled person's needs should be met, in this case, by going to a mother and baby unit. In ignoring the mothers' needs, refusing to go along with what the professional defines as 'good practice' and enforcing a logic of cost cutting and financial restriction, the manager is positioned as uncaring in an almost brutal sense. In contrast to Vicky's careful assessment there is the manager's categorical *'no'* (line 47).

Vicky judges the trumping of needs by the manager's financial imperative as 'appalling', generating predictably negative results for the disabled mother and her child (*'And very quickly he got (.) and he got (.) hit (1) and very quickly the baby went into care (.) and the baby's in care now (.) and is up for adoption as far as I know*, lines 38-39). Moreover, using the passive voice in this part of the extract, and obscuring the agency of the person (the father) who does the hitting further imparts a sense of inevitability that negative outcomes will accrue when professional judgement is ignored.

Vicky's act of resistance described in this passage involves her sticking to her professional views and insisting on recommending what she saw as the preferable service option in the face of her management directives. She positions herself as a 'champion of need' (Syrett et al., 1997: 155). However, the mother's own estimation of her needs is not given much space in this account. Vicky expresses a good deal of uncertainty whether the mother would have agreed to go to the mother and baby residential unit in any case, even though Vicky had identified that this was what they most 'needed' (*'If they were on their own (.) maybe they (.) wouldn't have gone into the mother and baby without the partner (.) or (.) or maybe they wouldn't have agreed to go into residential'*, line 34-36).

Positioning herself as an autonomous professional with expert knowledge may give Vicky the speaking rights to draw critical attention to organisational practices which obstruct her independent authority to use skill and judgement to assess and intervene with clients. However, the mother is positioned as rather a passive spectator to these struggles.

There are other contexts in my interviews where participants identify themselves more closely with parents with learning disabilities, and I contend that these ways of constructing the professional role can open up different understandings of these parents and of children, which I discuss below.

11.5 All Parents Together

This section focuses on my interview with Tania, a social worker in a children and families social work team. Tania describes her involvement over one year with Maggie, a mother with learning disabilities, who eventually lost custody of her four children, following a Social Services assessment. In line with the construction of parents with learning disabilities making unreasonable financial demands on services, Tania herself begins by positioning Maggie as a 'drain on resources'; someone with a seemingly never-ending capacity to absorb services.

In her initial description of Maggie and her difficulties, Tania makes an 'extreme case formulation' (Pomerantz, 1986). Potter and Wetherall explain that '*extreme case formulations take whatever evaluative dimension is being adopted to its extreme limits*' (1987: 46). This device may be used to try and convince the listener of the overwhelming causal constraint that the circumstances enforced on the narrator.

Extract 11.vii Tania, children and families social worker

1 2 3	T:	She had very very poor negotiating skills [...] She had a lot of (.) um (1) money management was terrible [...] Also it was complicated (.) you see (.) that she had (.) sort of mental health problems.

Maggie's difficulties are described as many, various, complex and extreme. For example, her negotiating skills were not only '*poor*', they were '*very, very poor*'.

Extract 11.viii Tania, children and families social worker

1 2	T:	There (.) had been a lot of input from us (.) there had been a family care worker going in for: about three years
3	D:	Was that once a week or something
4	T:	Yeah (.) well (1) Maria used to do more than that as well
5	D:	Right
6 7	T:	You know (.) at one point she was taking (.) I mean (.) we got nursery provision for all four children
8	D:	[Okay
9 10 12	T:	[Well for the two youngest ones (.) and (.) the two older ones were at school (1) and the mum couldn't get the four of them into school or into nursery by nine o'clock
13	D:	Right
14	T:	It was literally ten minutes walk (.) you know
15	D:	Yeah
16 17	T:	(.) Er (1) so: at one point Maria was picking up the children and taking them for the mum (,) and (.) and again picking them up from school=
18	D:	=Yeah
19 20	T:	Helping with basic routines (.) but it ended up that Maria just (.) did it (.) you know (2) um and financially (.)
21	D:	Yeah
22 23	T:	We gave so much Section 17 funding (1) it was creating this dependency that more money was going out

Tania is arguing that she and her colleagues did all they could, but they were doomed to failure, because of the Maggie's personal characteristics. Emphasising the intractability of the case by invoking a list of 'tried and failed' interventions (White, 2002) also prospectively accomplishes a form of self-exoneration and limits what the listener is likely to expect of the practitioner who has already exhausted all the possibilities. Tania stresses the nearness of children's school (*'it was literally ten minutes walk'*, line 14); Maggie therefore had no reasonable excuse for failing to get her children to school on time. Tania describes support 'beyond the call of duty', with people like Maria, the family care worker, putting in overtime with Maggie. In addition, Maggie was unable to generalise from

what was being demonstrated to her by Maria, so she was unable to use these skills when she was left on her own.

So instead of achieving the desirable goal of Maggie becoming more skilled and independent of services, so that services could reduce their input, Tania saw services reinforcing what she names '*a culture of dependency*'. Here, the organisational structures that underlie Tania and Maggie's relationship are defined. Maggie is positioned as not only 'needy', but 'greedy'. Services expect that clients will be able to use resources as a means to change their behaviour in a once and for ever pattern (like learning to use the bus?), becoming less needy as time goes on.

Later, another discourse emerges, where the subjects in the discourse assume rather different positions. As we talk, Tania admits that she did not agree with the outcome of the assessment, and the decision for care orders to be requested for all of Maggie's children. She says that using care orders was '*like using a hammer to crack a nut*', and she would have been a lot happier if supervision orders had been sought for the two older children only, so that Maggie would look after her two younger children full-time, with the older ones returning to her home over the weekends.

In this discourse, Maggie is positioned as someone who has not been assessed fairly and objectively, but who has been set up to fail by services which place her in situations where she is bound to appear in a bad light.

Extract 11.ix Tania, children and families social worker

1	T:	When I was going on maternity leave (.) there was a (.) handover
2	D:	Hmm
3	T:	And it was very hot it was like in the summer (2) and they did it at what time (.)
4		about quarter to four (.) four o' clock
5	D:	Right
6	T:	The children would have been at nursery (.) nursery or school all day (.) they
7		were tired (.) they were hungry (.) they (.) were thirsty (.) [They
8	D:	[Yeah
9	T:	They didn't know why they were there (.) and (1) you had children
10	D:	Hmm
11	T:	You had what (1) a three year old (.) a four and a half year old a (.) a seven
12		year old and a ten year old

13	D:	Hmm
14	T:	All hadn't seen their mum all week (.) all demanding her attention (1) um (.)
15		and then it was like this mother isn't able to meet their needs (.) [but
16	D:	[yeah
17	T:	I would like to see which mother was (.) able to meet those needs (1) it was
18		just (1) you know (2) I just felt that she was (.) sort of (.)set up to fail really

To reinforce her 'Set up to Fail' argument, Tania describes a situation in which Maggie was placed, where Tania feels that 'any mother' would have failed. Tania piles up the factors which were likely to make the contact meetings a failure; the hot weather, the timing of the visits just after the end of the school day when the children were tired, hungry and thirsty (lines 3-14). She is defining Maggie primarily as a mother like any other; a mother like Tania herself. Tania describes an almost exactly parallel situation, in which she herself felt that because of the presence of a judging 'other' her own family performed in a way that seemed quite disturbed and out of control.

Extract 11.x Tania, children and families social worker

1	T:	I mean if we have the Health Visitor come round to <u>our</u> house with one three
2		year old and one is one (.) like a wild thing ((laughs))
3	D:	((laughs))
4	T:	And I mean (.) it just changes the dynamics of the (.) the family having a social
5		worker in
6	D:	Yeah
7	T:	And I mean (.) Mum must be much more uptight (.) and the children sense
8		that
9	D:	Yes I'm [sure
10	T:	[And I mean (.) I think that I'm a lot more tolerant than (.) [or I'm less
11	D:	[Yeah
12	T:	(.) Judgmental of what the Mum's doing than other social workers that haven't
13		got children (.) you know
14	D:	Hmm
15	T:	I mean (.) I've read reports and (.) they've described what my three year old
16		regularly does and called it sort of (.) <u>disturbed behaviour</u> ((laughs))

Tania describes the way that she uses empathic understanding of Maggie's situation to render the way she is with her children understandable and unproblematic. Maggie's difficulties are seen as at least in part created by the spotlight that services shine on her during their assessments, and Tania maintains that a similar scrutiny would condemn her as an unfit parent as well.

Tania positions herself much closer to Maggie, on the basis of their shared experiences, whereas services (perhaps specifically in the person of social workers who are not mothers and who are likely therefore to be more 'judgmental' and unforgiving) are positioned as distant, unfair, and discriminatory. Life experiences (or lack of them) are admitted as having a bearing on the sorts of judgements that social workers make. Moreover, the process of assessment, instead of being objective and impartial, with its 'checks and balances' (as Tania puts it), seems to create situations which every mother would fail.

Where Tania talks about these checks and balances, the two discourses, and sets of positions are most clearly juxtaposed:

Extract 11.xi Tania, children and families social worker

1	D:	It sounds like you accept that things that she did (.) you (.) weren't happy with and
2		they weren't good for the children (1) and yet (.) you disagreed with your colleague's
3		decision
4	T:	Yeah
5	D:	That she'd sort of (.) crossed the line into doing something that meant that she
6		couldn't be with her children (1) how (.) how do you sort of (.) decide on that (.) um I
7		mean it sounds like such a grey area
8	T:	(1) I mean there should be checks and balances (.) you know (.) [I suppose
9	D:	[Right
10	T:	With the supervisor's report
11	D:	Yeah
12	T:	You know (.) there was another senior assessment worker doing a separate
13		assessment
14	D:	Right
15	T:	But I just (1) [I don't know
16	D:	[Hmm
17	T:	Perhaps I got too involved or I felt (3) you know (1) I just thought that she was a
18		woman that really did care for her children
19	D:	Hmm
20	T:	You often (.) in this job you often see parents that don't (1) and (.) wants to try you
21		know (.) to the best of her ability (.) wants to keep things together

The first discourse focuses on Maggie's disabilities and lack of skills and the way she does things wrong. Tania is positioned as an apologist for services which do their very utmost to help Maggie to no avail, and whose assessment is held to be fair and objective. In the second discourse, Tania is present, like Maggie, as a mother who takes a more sceptical position vis-à-vis services. The focus is more on Maggie's positive feelings towards her children, and her efforts to use the abilities and

resources that are available to her in order to care for her children. This discourse takes a 'competency perspective' (Booth and Booth, 1994), highlighting Maggie's strengths, rather than a 'deficiency perspective' which accentuates her lack of skills. In particular, Tania draws attention to the less tangible and measurable aspects of parenting; Maggie's commitment and involvement with her children, and her determination to do her best.

Tania acknowledges her personal interest in this 'case' and worries out loud that perhaps her understanding of Maggie's point of view came from feeling '*too involved*' (line 17). This is an example of what Potter (1996) calls stake confession where a speaker concedes a personal interest in constructing a particular version of events, specifically when issues of stake and interest are so salient that she is unlikely to be able effectively to occupy a 'neutral' position. Moreover, by drawing attention to her perhaps excessive level of interest, Tania highlights the honesty and self-awareness implicit in her account and takes the wind out of the sail of potential objectors by conceding a point in advance.

However, it is also possible that invoking emotion in what White (2002) calls 'affective judgement' or the practitioner's 'feel' for a family can be accepted as part of professional competence within 'ecologies of practice', though not the sort of competency that fits in with the 'scientific-bureaucratic' model of 'evidence-based practice' whereby algorithms for making decisions and determining interventions is linked to 'objective' research findings achieved by academics. There is a growing approval of the idea that professionals can profitably put aspects of their out-of-work experiences into service in their professional lives, with an expanding literature on the use of self in social and health care practice (Payne, 1997) including practitioners' experiences as parents (Zubrzycki, 1999).

Moreover, when she positions herself as a mother in her interview, Tania works up her category entitlement (Potter 1996) which allows her to claim a particular kind of authority by virtue of belonging to the category of

'mother'. From her standing as a mother, Tania contrasts her insights into Maggie's situation and her appreciation of her as another mother trying to do her best, with the more blinkered perspective of other workers who are not parents. Contrasting hard-won experience with theoretical or 'book' knowledge is an effective way of advancing a particular set of understandings. Gloria endorses this argument when I ask her if she thinks it makes any difference when a professional is a parent.

Extract 11.xii Gloria, health visitor

1	G:	Yes because um it gives you (.) um a clearer insight
2	D:	Hmm
3	G:	Some sort of (.) vision about parenting because you've had the practical
4		experience
5	D:	Hmm
6	G:	And:: (.) um it helps you to empathise with clients (.) with certain (.) with their
7		experiences
8	D:	[Yeah
9	G:	[And (.) it (2) prevents you from just working on a theoretical basis

11.6 The 'normal difficult child'

In the following passage, Brian explores the possibilities and limitations of what Gloria describes as the empathic understanding of clients as fellow parents.

Extract 11.xiii Brian, children and families social worker

1	D:	OK (1) I mean (1) I don't know if (.) you are a parent yourself
2	B:	((Nods))
3	D:	You are (1) I mean (.) has that made a difference to you in the way that you
4		work with parents generally (.) or you (.) sort of work with parents with learning
5		disabilities
6	B:	(.) It's made a difference with how I work with parents in general (.) especially
7		with single parents because I realise just how difficult it is
8	D:	Right
9	B:	(.) I mean (1) I don't think I thought it would ever be easy bringing up five
10		children or that (.) one child even on your own on income support was an easy
11		task (.) but (.) um (3) exactly what it's like to have a child
12	D:	Yeah=
13	B:	=it's not just up there ((points to head)) (.) you've got it in your heart
14	D:	Hmm
15	B:	You know what it feels like to look after a child (.) you know what it's like to be
16		up in the middle of the night with a crying child or (.) or a child that won't eat
17	D:	Right
18	B:	Or a child that's just being a pain in the arse
19	D:	Yeah (1) I mean (.) do you find that you use those kinds of experiences in your

20		work
21	B:	(1) To some extent (2)
22	D:	[Right
23	B:	[I mean (1) I don't try to because I feel that my experiences are very different to
24		my clients
25	D:	Yeah
26	B:	I mean (.) I'm earning decent money I've had a decent childhood I've got self-
27		esteem (.) I've got a partner I've got (1) I've got all sorts of things (1) I mean (.)
28		I think it's really patronising to try(.)
29	D:	Hmm
30	B:	To some extent to say that you know what they are talking about (.) because
31		you don't (.) ((inaud.)) I don't know what it's like not to have a partner to bring
32		up a child without a partner I don't know what it's like not to have a decent job=
33	D:	=Right
34	B:	Or no prospects (.) or no self-esteem

In lines 9 and 10 Brian talks about the generalised knowledge he had about the 'tasks' of parenting in difficult circumstances before he became a parent himself. But the long pause at line 11 signals a shift into a different discourse, that of self-confession. Brian indicates that he is going to tell me a more profound truth about being a parent – '*exactly what it's like to have a child*' (line 11), instead of dealing in generalities. Like Tania and Gloria, he then contrasts intellectual knowledge or theoretical knowledge with the lived experience of 'emotional knowledge' which is enacted through actual childcare practices.

Extract 11.xiii Carol, advocate

1	D:	(1)do you think your own experiences of having pregnancies and being a
2		mother has had an impact on on how you've worked with parents with learning
3		disabilities
4	C:	Oh yes I think so
5	D:	Hmm
6	C:	Um (1) unless you've been there you don't know how hard it is
7	D:	Hmm hmm
8	C:	And it is so hard for (.) it was so hard for me (.)
9	D:	Well I'm a mother too so I know ((laughs))
10	C:	I found it really really hard
11	D:	Yeah
12	C:	For loads and loads of different reasons and both girls were completely
13		different
14	D:	Yeah
15	C:	But each of them was really easy in some ways really hard in other ways

Whereas Tania talks about how all children can seem wild and out of control in particular circumstances, Brian and Carol propose that 'normal' everyday parenting is beset with struggles. In both accounts, the child who emerges in these self-disclosing discourses is the child who presents

difficulties as a matter of course; who won't sleep or eat, or comply with adults' requirements. This is a rather different understanding of 'the child' than the constructions we have met in earlier chapters where children's vulnerability, their need for special inputs and protection from harm were emphasised. Talking from their own experiences as 'All Parents Together' having similar experiences as their clients, the professionals present the idea that children can be challenging and exasperating as part of the everyday vicissitudes of parenting.

The person who has this knowledge of the 'normal difficult child' has more authentic and privileged knowledge, which is only accessible through experience , as Carol says, '*unless you've been there you don't know how hard it is*'. For Brian, this is 'heart-felt' knowledge (line 13), embodied and embedded in the corporeal self and therefore more genuine and authentic. But then, by laying claim to this authentic, feeling self, Brian opens up other subjectifying possibilities which he takes pains to resist. Because if Brian's heartfelt knowledge lays claim to privileged authenticity, the implication is that it has universal relevance and the insights Brian has gained from his lived experience can be applied to the people that he works with. They can be understood as 'just the same', 'All Parents Together'.

Potentially this seems to be an equalizing, non-hierarchical discourse, that part of being human is having fundamental experiences that bind us together and create a common language with which we can understand the lives of people different to ourselves. Presumably, through reflecting on the realities of our lives as parents we can find common cause with other marginalised parents, such as parents with learning disabilities. We apply the same standards to them that we apply to ourselves. There are implications about how far parents are therefore morally culpable for less than perfect parenting practices. As professionals we acknowledge that our own children are fractious, even unmanageable at times; how can we judge parents with learning disabilities as inadequate when our own efforts to live up to idealised theories of parenting fare no better?

However, when I ask Brian (line 19) whether his own experiences as a parent guide his practice there is another pause. There is the sort of shift in tone and language that occurs at this point which illustrates what Fairclough (1992: 230) has called 'cruces' or 'moments of crisis':

> *These are moments in the discourse where there is evidence that things are going wrong: a misunderstanding which requires participants to 'repair' a communicative problem...exceptional disfluencies (hesitations, repetitions) in the production of a text; silences; sudden shifts in style'*

Fairclough has suggested that to focus on such moments of crisis brings to the fore aspects of practices that might otherwise be taken for granted as normal and expected. The moment of crisis signals a point of contradiction or struggle and shows discourse users dealing with these problematic features within a discourse.

Instead of embracing the 'All Parents Together' discourse, Brian rejects it. He criticises it for being glib and '*patronising*' (line 27). He does this by particularising his own experience of being a parent. Instead of using the generalising 'you' as in the earlier part of this passage, he switches to the unique specificity of 'I'. He is not laying claim to the authority to speak on others' behalf (Fairclough, 2001). He uses a number of 'I' statements to underline the structural differences between his experiences as a parent, and those of his clients. Far from bringing people together, here Brian is emphasising how lived experience in a society which is riven with accumulating structural inequalities makes it harder for people to understand each other. In fact, Brian emphasises the limits of empathy and questions how far we can ever understand each other.

Therefore, the danger of the 'All Parents Together' discourse is that it refers to 'common sense' assumptions of what being a parent is about, and that it presupposes that there are experiences, values, feelings and identities that are shared by all parents; or at least those who are 'proper', normal parents.

Thus, reflective use of personal experience is seen as a potentially tricky strategy, and one which might accentuate divisions between professionals and parents. After endorsing the usefulness of having experience of the 'emotional side' of parenting as a resource to understand other parents, Gloria, a health visitor, explicitly questions the idea that personal experiences of being a parent create a more tolerant and empathic approach among professionals, by challenging the concept of a 'normal' family life which structures family life in a universal sense.

Extract 11.ix Gloria, health visitor

1	G:	And for me it was very valuable (.) because a lot of the (.) emotional side of things that
2		you feel
3	D:	Yeah
4	G:	Or that you can feel after you've had a baby (.) or how you do feel managing children
5		who won't sleep (1) but (.) I suppose it depends on your experience really and your
6		child=
7	D:	=Right
8	G:	You can have an easy (.) time of it and a brilliant baby and (.) you don't have to
9		struggle up the stairs to flats and have it really easy (.) then (.) that could give you a
10		false picture
11	D:	Right (.) so (.) so you could be (.) harder on some parents
12	G:	You could be (1)
13	D:	[Hmm
14	G:	[If you had what you call a normal sort of time (.) it might be normal to you [but you
15		[Yeah
16	D:	
17	G:	Might actually have had quite an easy time

Harnessing the 'All Parents Together' discourse allows the professional to lay claim to a deeper, emotional understanding of parenting and a more 'realistic' view of children that cannot be found in a text book. However, Gloria suggests that it can lead to professionals becoming more, rather than less judgemental if they generalise from their own experiences as parents.

Extract 11.xv Sophie, health visitor

1	S:	I mean, I have a baby of eight months old, so I'm a new parent
2	D:	Gosh (.) right (.) I mean do you think it has made a difference
3	S:	(1)I don't think it has affected my practice at all (.) no I really don't
4	D:	Yeah
5	S:	(1) It has just made me feel (.) just made me even more aware of how vulnerable
6		children are
7	D:	Really (.) has it changed your feelings (.) I mean (.) maybe not practice (.) you know

8		(.) you still practice in the same way
9	S:	Hmm
10	D:	But do you think for you (.) it changed your feelings in terms of understanding
11		vulnerability in a sort of (.) more personal way
12	S:	(2) I think it is much more an emotional thing when you become a parent yourself (1)
13		um (.) [there are some child protection cases which are quite
14	D:	[Hmm
15	S:	Upsetting
16	D:	Right
17	S:	When you have just had your own baby you find them even more distressing I
18		suppose
19	D:	Yes (1) you mean when parents and children are separated
20	S:	No (.) not so much that (.) when you know what's happening with the children

Sophie explains that reflecting on her experiences as a parent has changed how she feels in relation to child abuse and neglect. It has intensified the salience and centrality of the construction of the children she works with as vulnerable, at risk and in need of protection. Mobilising her personal experiences brings home to Sophie the damage done to children and causes her 'upset' and 'distress'. There is an implied contrast between the love and care that Sophie would give to her own baby, and the falling short of parents with learning disabilities in failing to provide this for their own children.

11.7 Competencies 'against the odds'

I have already pointed out how the 'All Parents Together' discourse presented Tania with opportunities for noticing and drawing attention to the strengths and dedication of Maggie, a mother who *'really did care for her children'.* The next two extracts also focus on the competencies of two mothers with learning disabilities.

Extract 11.vi Kelly, family support worker

1	K:	The two babies (.) the twins have been adopted out.
2	D:	Oh right
3	K:	And that is currently going on at the moment
4	D:	Were you there when she had them
5	K:	No (.) they must be almost a year (.)
6	D:	Right right (.) gosh (.) that family has been through an awful lot.
7	K:	Yes ((laughs)) an incredible lot
8	D:	How (.) do you think it has affected them
9	K:	(1) Yvonne has blocked it all out (.) to a certain degree (1) but when he turned
10		up on the doorstep (.) the ex-partner (.) she completely (.) you know (.) lost it

11	D:	big time
12	K:	Right
13	D:	But I think it was also a good thing because (.) [she survived it.
14	K:	[Hmm
15	D:	She did all the things that she needed to do
16	K:	Right
17	D:	And I think (.) having an experience like that is more positive than never having
18	K:	it
19	D:	Yeah=
20	K:	= B (.) because it has happened (1) she coped (.) she survived
21		Hmm
22		And now that it has happened again though (.) some months along she (.) she
23	D:	coped with it much better this time and she knows she can do it (1) she (.)
24	K:	knows [She can
25	D:	[Yeah
26	K:	Handle it

Extract 11.xvii Rachel, advocate

1	R:	And um (1) just watching her self-esteem grow [has been absolutely
2	D:	[hmm
3	R:	Fantastic and her beginning to take control (.)
4	D:	Hmm
5	R:	And to question things and to you know (.) she's really really (1) blossomed
6	D:	Hmm
7	R:	And it and that is really lovely
8	D:	Yes
9	R:	And she has managed to keep two of her children [she's had to make
10	D:	[Right
11	R:	Really difficult decisions
12	D:	Yeah
13	R:	Um (.) and it's er and she's now going to college
14	D:	Okay
15	R:	And she's coping on her own
16	D:	Hmm
17	R:	You know she's doing really really well and she's actually done some training (.) with
18		us

In extract 11.xvi, Kelly, a family support worker starts by telling me about how Yvonne's twins were taken away from her for adoption (her older children were left in her care). This is a dramatic event that is likely to position Yvonne as a failed mother and person and by imputation a dangerous and potentially abusive parent. My response to this removes the focus from Yvonne as a 'failed parent' (*'that family has been through an awful lot'*, line 6) and instead positions her as on the receiving end of difficult life events. Yvonne's confrontation with her ex-partner, as described by Kelly, was another potential difficulty, but one which Yvonne managed to overcome, even developing strengths and confidence as a result. Rachel describes a similar trajectory for the mother she has been

working with, whose exposure to difficult circumstances has led to a growth in her '*self esteem*' and assertiveness.

These accounts reference rather different constructs of parents with learning disabilities as 'copers' or 'survivors' of difficult experiences. The mothers described here have not only 'survived' traumatic life experiences such as confrontations with abusive male partners, but also contact with services who have with which they have been involved in struggle and confrontation ('*And she has managed to keep two of her children'* line 9). These constructions therefore may reference two different sorts of 'survivor' discourses. The first is familiar from feminist 'survivor' literature, particularly relating to experiences of sexual abuse or domestic violence. Claiming the status of 'survivor' involves women standing up against their abusers and rejecting the status of passive 'victim'. Women who are positioned as 'survivors' in this way may be seen as brave and commendable by an admiring audience, though they may also expose themselves to voyeurism and trivialisation, and personalisation of the traumas they have experienced (Alcoff and Gray, 1993).

A different sort of survivor discourse has been used by people who have used mental health services, who describe themselves as 'system survivors' (Beresford and Wallcraft, 1997). Here, the mental health system is seen as oppressive and more or less a barrier to healing and wellbeing, rigidly enforcing ways of relating to mental illness as individual pathology, divorced from social meaning, ways which 'survivors' have challenged and disputed. Linda, the mother Rachel talks about in Extract 11 xvii is described as having grown in assertiveness and autonomy in the wake of her encounter with statutory services.

11.8 Concluding remarks

I found this chapter the most difficult one to write. I found myself constantly examining my own motives and assumptions in drawing conclusions from the published literature and my own data. I felt the need to try to answer the question whether there can be relationships of alliance and collaboration between disabled people and practitioners, which are not marked by professional dominance and control, for instance under the guise of 'empowerment' or 'skills building' Even the complimentary and positive tone adopted by Kelly and Rachel in the last two extracts may reflect more complex and contradictory constructions of parents with learning disabilities.

Working from the analogy of the examination of the position of men within the women's movement, Marks (1999) has speculated on the roles that people without disabilities might adopt within the disabilities rights movement, and more generally in the company of disabled people. She talks about how men or nondisabled people might adopt the stance of 'guilty admirers' (Jardine and Smith, 1987), who see women/disabled people as noble victims with special sorts of strength and resilience, originating in their experiences of oppression. This hypothesis seems to suggest that non-disabled people can find something almost attractive in the 'otherness' of people with disabilities. Perhaps interacting with them assures non-disabled people of their wholeness and power. Alternatively, non-disabled people might find that through the process of projective identification, in other words, misidentifying unpalatable personal attributes as belonging to other people, aspects of themselves which feel needy and inadequate can be overlooked as they concentrate on others' inadequacy.

Both these constructions depend on relating to people with disabilities as clearly 'other', outside the immediate subjective experience of 'non-disabled' people. Marks (1996a) has challenged this by advocating that people without disabilities refer to themselves as 'Temporarily Abled

Bodied' or TABs. She argued that disability may well be part of the futures of many of us, if not part of our present experiences. If there are two worlds or two cultures, that of the able and the disabled, those of us who are 'able' can cross into the world of disability, as a result of illness, injuries, or increasing age. Thus, our residence in the world of the able is only temporary and the dividing line between the two 'worlds' is hazy and shifting. As Sinason (1992) we are all faced with limitations in our cognitive abilities, and the common defensive strategy of failing to acknowledge these will only handicap us further. Disability is therefore no longer something that can be located only in the Other, but becomes part of our own embodied existence and future potentialities. This argument helps us identify the strengths of the 'All Parents Together' discourse that I have described in this chapter. I concede the force of Brian's argument that as middle-class professionals we (myself and the participants in this study) are insulated from many of the experiences of social exclusion, poverty, social isolation and discrimination that mark the everyday lives of many parents with learning disabilities. However, we are all subject to some extent to many of the same processes of disciplinary control which define and restrict the kind of parents we can be, though those with privileged access to status and authority are more likely to be able to resist these.

Moreover as professionals we also have to come to terms with the limitations and the constraints which create barriers against the fulfilment of our potentialities as effective practitioners in our working lives. We often fall short of what we hope to achieve both in the process and outcome of our work. It may be external constraints which disable us as professionals, the 'economies of performance' which have narrowed the range of possible relationships and interventions with clients to those which can be measured and risk- managed, delivered within ever-shrinking budgetary and time limits. Perhaps more difficult to identify and recognise are the internal constraints which disable us; the limits of our knowledge, skill and confidence, and the disciplinary practices which have become second nature, part of our everyday 'habitus' (Bourdieu, 1990).

Chapter Twelve: Conclusions

12.1 Introduction to Chapter Twelve

This study advances a new and original approach to investigating how parents with learning disabilities are understood by professionals. I use a social constructionist orientation to connect perceptions of these parents to mainstream debates about the underlying cultural constituents of personhood, about the nature of parenting and of children, and about the role of human service professionals in contemporary social arrangements. Thus the conclusions of this study have a significance beyond the confines of learning disability studies. In the accounts of the participants, we have come across examples of quite extreme difficulties encountered by parents and their children, as well as by the professionals who work with them. However, these narratives, and my analysis throw light on the more general difficulties, contradictions and dilemmas, which are part of 'normal' everyday family life and professional practice.

The existing research to date focuses on the gap between professional evaluations of learning disabled parents and the prospect of these mothers and fathers enjoying the status of 'proper parents'. We have moved beyond the overtly eugenic perspective which denies the fitness of people with learning disabilities to bear and raise children under any circumstances. Nevertheless, the 'parent with learning disabilities' is still

constituted as a social problem, whether the solution to this 'problem' is sought through immersion in the routines of 'ordinary life', engagement in programmes of training and skills building, or resistance to disabling discrimination and restoration of human rights. Yet in the main these projects have failed to gain widespread acceptance, and this study has attempted to answer the question of why these parents continue to attract intense negative attention. I contend that the way that these parents are being constructed by human services professionals continues to trouble and unsettle dominant discourses about 'responsible parents', 'a normal childhood' and 'the empowering modern professional' and even fundamental, taken-for-granted concepts of what it means to be an autonomous social actor in civil society.

12.2 Findings of the research

In this section I review and address my original research questions. Through the process of conducting the research, reflecting on the participants' accounts and fashioning the finished written product, I retained a core concern with investigating my three central points of focus, namely constructions of 'learning disabilities', of 'parenting' and childhood, and of professional practice. In addition I kept returning to the overlapping themes of **individualisation** (of responsibility and family life) and of **risk** which connected and intersected these constructions in sometimes contradictory ways. Here I summarise the findings of the research, relating them to the published literature and to these wider themes, before examining the limitations of this study and its implications for professional practice.

12.2.1 Research question 1

- How do professionals construct 'learning disabilities' when talking about parents with learning disabilities? What impact might ideas about parenting have on this process of construction?

In this study I have taken the perspective that 'learning disabilities' should be understood as a socially constructed category, rather than an objective diagnostic term which captures some essential characteristics of the individual. Thus 'learning disability' as a category of personhood is predicated by particular social arrangements and is talked into existence through referencing elements in the discursive economy which define and maintain the boundaries between 'normal' ability and incapacity. The term itself is of fairly recent historical provenance, in that people with this label have been known by other terms in the recent past, and has specific meanings and implications within contemporary social, economic and cultural arrangements.

In most of my participants' accounts, the construct of 'learning disabilities' was bound up with ideas of incompetence and deficit. Significantly, this construction referenced particular socially and culturally relevant conceptions of competence in terms of the demonstration of particular capabilities. Incapacity was presented as a lack of self-awareness and the absence of an ability to reflexively monitor one's performance in different settings. These capabilities have come to achieve particular salience in the post-Fordist era of 'late modernity' which demands a flexible, self-regulating workforce. Being seen as deficient in these ways positions these parents as naïve and immature social actors who are unable to proficiently manage their self-presentation. In my participants' accounts these parents were depicted as trying to bring off clumsy acts of subterfuge, to hide their 'true natures' and needs, not only from others, but also from themselves. Moreover, they were seen as being unable to anticipate and incorporate professional expectations of appropriate parental behaviour. This construction even closes off other possible interpretations of these parents' behaviour which might have been understood as demonstrating skill and adaptability. The emphasis on the parents' social incompetence also highlights the expertise of professionals and their skills in 'uncovering' hidden learning disabilities and exposing the truth of the parents' impairments.

Being seen as intellectually deficient according to this construction also limits the possibility that learning disabled people will be seen as adequate parents. I have traced the influence of a culturally pervasive model of 'developmentalism' as a way of understanding childhood. Childhood is seen as a process of progressive acquisition of skills and abilities along an expert-defined developmental trajectory towards adult competence. Moreover, competence is primarily defined in terms of increasing cognitive sophistication, autonomy and skill, with a particular emphasis on language acquisition as a key marker of 'normal' development. In Chapter Eight I noted how practitioners expected parents to make special specific accommodations in order to provide the 'right' sort of experiences which will aid children's cognitive development, and to prioritise these activities over other demands. There is a degree of inevitability therefore that being constructed as intellectually incompetent, these parents will be seen as incapable of advancing intellectual competence in their own children in these ways.

There was a general theme of professionals constructing time as a limited resource which could be conceptualised in money terms as 'hours of support' and an emphasis on short-term interventions with an expectation of rapid 'pay-offs'. Conversely parents with learning disabilities were constructed as intractably slow in their learning, needing a greater investment of time from practitioners, beyond the constraints of contemporary 'economies of performance'. These require the delivery of discrete and time-limited 'packages of care', whereas the consideration of these parents raises the spectre for professionals of limitless need and never-ending demands on their time and on the public purse.

12.2.2 Research question 2

- How do professionals construct 'parenting' and 'the child' when talking about parents with learning disabilities? What impact might concepts of learning disabilities have on the process of construction?

Participants in this study prescriptively placed parents and children within particular relationships relating to care, authority and need. Parents were expected to 'take responsibility' for children; to be in charge; to possess and demonstrate superior knowledge and skills; to meet children's 'needs'. 'Needs' were assumed to be objective requirements, without which children's development may stall and their well-being be compromised. I have already pointed out how prevalent discourses of 'developmentalism' assume that childhood is a process of 'becomings', a series of steps leading from vulnerability and incompetence towards full adult participation in civil society as skilled social actors. Participants' assumptions were that children would not proceed along these developmental steps without assistance from their parents, not only because special sorts of 'stimulation' were needed to potentiate development, but also because children's development was seen as dogged with risks. Even 'normal' development exposes children to dangers, from the everyday hazards of the home, which needs to be rendered 'child-proof' and safe for vulnerable growing children, to children's own risk-taking tendencies which have to held in check by responsible parents.

These constructions of parents and children were disrupted and unsettled when the parent had a learning disability. Practitioners feared that the 'natural order' of childhood is disturbed when children move outside the position of being recipients of care to being active contributors to family life. I have explored the cultural construction of 'young carers' of disabled parents: children supposedly denied a normal, carefree childhood centred on the satisfaction of their 'needs', because of their parents' falling short in their provision of care. I mentioned above that children were expected to develop in the direction of increased competence and skill, but only specifically within the sphere of 'appropriate' children's activities, not by taking on tasks and responsibilities that should be undertaken by their parents.

I was struck by how these constructions of 'proper' parenting with their emphasis on parents' obligation to ensure their children's cognitive

development downplayed the importance of other sorts of parental inputs, and how demonstrations of love, warmth and commitment and interest by parents with learning disabilities towards their children were seen as of secondary importance. By excluding consideration of expressions of parental love and concern from the arena of professional monitoring and intervention, practitioners may be protected from an engagement with the emotional trauma and distress experienced by children (and parents) when families are broken up. Although I did not specifically address this issue in my analysis, I am also aware that participants expressed little consideration of the way that bonds between parents and children extend throughout the life-course. The testimonies of adult children of parents with learning disabilities (Booth and Booth 1998; Ronai, 1997) attest to the importance of these lifelong relationships, even when they are marked by periods of difficulty, conflict and separation.

12.2.3 Research question 3

- How do professionals construct their own role when talking about parents with learning disabilities? What impact might concepts of learning disabilities have on the process of construction?

In this study I have explored the dilemmas and contradictions involved in professional practice with these parents. Drawing reflexively on my own experiences as a human services professional, I have rejected more one-dimensional conceptualisations of professionals as either the altruistic public servants of classical functionalist sociology, or the oppressive parasites on disabled people described by some writers on the social model of disability. Professionals operate in a social field where expertise is often seen as suspect and elitist, but also where experts of human interaction and behaviour are invited to pronounce on ever-expanding areas of our private lives. The archetype of the 'Hunch-Shouldered Authority' (Billig et al., 1988) personifies the way that professionals may attempt to address these dilemmas, by subtly shaping 'clients' in their own

image as self-managing and 'empowered' consumers of services. I have examined how participants prioritised 'empowerment' as a goal of their interactions with parents, while struggling with issues of dependency, personal closeness with their clients, and trust.

By deconstructing the concept of 'empowerment' in Chapter Ten, I concluded that 'empowered' parents were not to be expected to be released from professional surveillance and control. They could not escape the disciplinary webs of power/knowledge which construct them as good or bad parents according to how far they complied with meeting their children's 'needs' as defined and evaluated by professionals. Parents with learning disabilities challenged the 'empowerment' agenda by appearing to professionals as incompetent clients. On the one hand, professionals felt these parents did not share understandings of children's needs and appropriate patterns of family life, on the other hand, the parents were not seen as presenting within the client/practitioner relationship as 'partners' with the desirable levels of autonomy, knowledge and skill.

Professionals faced different dilemmas as a consequence of having to operate within the 'Risk Society' (Beck, 1992) where a breakdown in the old certainties and traditional scripts relating to such wide-ranging social fields as family life, the economy and even the rhythms of the natural world has led to a climate of uncertainty and anxiety where risk management becomes a key personal task in managing the vicissitudes of everyday life. I described how ideas of risk have combined with discourses of developmentalism to redefine the responsibilities of parenting. The concept of risk has also become a key component in defining the boundary between private family life and state control and intervention, and this process has been reinforced by public debates and by developments in legislation and professional practice. Where parents with learning disabilities are judged as failing in their ability or willingness to assess and address issues of risk, the stage is set for the state to step in. In Chapter Nine I explored how professionals constructed their role in terms of a requirement to act decisively under these circumstances,

though they may have expressed varying degrees of ambivalence about this requirement. An even more unifying concept was that of subjection to professional jeopardy in this climate of risk and contradictory expectations of professionals. Participants constructed themselves as powerless in the face of constricting procedures, which prioritise risk assessment and management over family support orientated professional practice. Moreover, they positioned themselves having to be constantly on guard against imputations of down-playing or ignoring risks and as vulnerable to public censure or vilification if 'something goes wrong'.

12.2.4 Research question 4

- What possibilities for professionals' practice do these constructions open up or close down? What are the possibilities for resistance and the emergence of more positive and enabling constructions of parents with learning disabilities?

Professionals described the sorts of practices which linked to the discourses they employed, and others might be implied. More restrictive and controlling practices are likely when professionals lack confidence in parents' abilities, overlook structural barriers as well as potentials within the wider support system and are see prevention of risk as the highest order of priority. Professional intervention will then concentrate on bringing parents into line with dominant conceptualisations of 'normality' in family life through more or less subtle methods from guidance and offering advice, to employing more punitive sanctions or punishments. However, the dilemmas and contradictions within and between discourses that I have identified can make professional decision making more difficult. In Chapter Seven I described how Helen's dilemma in trying to reconcile her perceived responsibilities to promote expert-defined parenting behaviours with an agenda of 'respect' and 'equality' for disabled people could be paralysing and lead to uncertainty and inactivity.

This study has examined not only how professionals construct parents with learning disabilities in their talk, but also how they construct themselves and their practice in the context of their work with these parents. One major criticism of Foucault's analysis of power and discourse is that it seems to leave little space for the possibility of change and transformation. If the subject is constituted through discourse through the process of being known and talked about, how can she resist this process? Even types of power/knowledge which seem to offer opportunities for autonomy and self-determination, seem only to bind the subject more tightly in a regulatory web which is all the more intrusive and pervasive, because the subject herself is recruited as an active participant in self-regulation and self-government (Rose, 1996; 1999) .

Although Foucault himself did not advance an explicit theory of resistance, and has been criticised for implying that people are manipulated by power, even when they think themselves to be most free, there are potentialities for understanding resistance in his work.

At the same time that discourses make possible particular identities and activities they also exclude other possibilities of thought and action. As discourses privilege the speaking rights of particular actors, others are marginalised and ignored. But the process of exclusion creates a focus for alternative and oppositional discourses. Thus characterising people with learning disabilities as incompetent and inarticulate has not been able to forestall the growth of the self-advocacy movement (Goodley, 2001), or the expansion of interest in narrative and autobiographical accounts of the lives of these people (Ramcharan et al., 1997). Moreover the points of resistance can be local, transient and 'immediate' (Foucault, 1982) and may be overlooked in our search for grand, overarching movements of liberation.

I suggest that understandings of parents with learning disabilities informed by the social model of disability can constitute a form of resistance to

individualising discourses of incompetence. In terms of professional practice this approach promotes a tolerance of difference and recognition and opposition to the entrenched and institutionalised nature of discrimination against disabled people. Their access to services and support is seen as an entitlement, and not a privilege within the gift of expert non-disabled practitioners.

In contrast to this position, Jill's narrative in Chapter Eleven provided an example of how discourses of expertise and professional authority might be deployed in alliance with parents with learning disabilities to resist inequities imposed by managers. This illustrates Foucault's point that discourses have unexpected consequences. The possibilities opened up by a discourse are not necessarily determined as positive or negative. A discourse of professional expertise which in one setting can be limiting and repressive can in other offer opportunities for resistance.

> *Discourses are tactical elements or blocks operating in the field of force relations; there can exist different and even contradictory discourses within the same strategy; they can, on the contrary, circulate without changing their form from one to another, opposing strategy* (Foucault, 1981; 101-2).

However, in the example of Jill's narrative it proved very difficult for the professional to occupy the expert position while at the same time promoting the choices and decision making of the parent with learning disabilities. This strategy preserves the distance and power imbalances between professional and client. In Chapter Eleven I suggested that professionals could construct relationships of identification and empathic understanding of these parents through the employment of the 'All Parents Together' discourse. Laying claim to private identities as mothers or fathers themselves allowed practitioners to tell 'heartfelt' narratives of the complexities of family life. Their accounts created opportunities to recognise parents' strengths and competencies 'against the odds', including an appreciation of less tangible and measurable aspects of parenting relating to love, commitment and concern. However, it is important to recognise the limitations of this strategy; as some participants

pointed out, speaking from the position of parents themselves can lead professionals to judgemental and blaming evaluations of parents with learning disabilities.

12.3 Limitations of the research

In this section I identify the limitations of this research and its findings; the boundaries of its knowledge claims which have been imposed by its design and execution and by its theoretical and methodological underpinnings. For Willig (2001: 10) this activity comes under the heading of **epistemological reflexivity**, a consideration of the ways in which the research questions have defined and limited what can be found; how the design of the study and the method of analysis have 'constructed' the data and the findings; how the research question could have been investigated differently and what different understandings might have arisen as a result.

12.3.1 Social construction and 'real life'

First it is worth reiterating that this research does not claim to be an accurate reflection of what professionals actually do in real-life situations. This limitation is imposed by the epistemological assumptions behind the methodology that I used. The social constructionist framework of the study meant that the research questions were framed as inquiries into how phenomena are socially and discursively constructed, specifically within the research context. From this methodological position, the interview situation is regarded as a social interaction between research participant and researcher and the resulting data should not be seen as providing straight-forward descriptions or explanations of behaviour, but rather '*a situated appeal to the rationality and moral appropriateness of the behaviour*' (Silverman, 1993: 200). Participants are assumed to be concerned with how they manage their stake in the interview as an

interviewee, taking into account how they construct the orientation and intentions of the interviewer (Jorgensen, 1991; Willig, 2001).

This methodological stance can have ethical implications. Concentrating on how narratives are constructed may encourage a detached and 'ironic' stance. I have criticised professionals for trying to avoid acknowledging the depth of emotional relationships between parents and children. There is also a danger that as a researcher I myself become caught up in the intellectual endeavour of deconstruction and downplay the distress, confusion, and experiences of loss of people being described. A different research approach would have brought these experiences to life in a more vivid and immediate way, though perhaps at the expense of an analysis of underlying relations of power which perpetuate the inequalities which underpin these negative life experiences[1].

12.3.2 Generalisability of research findings

In Chapter Five, Section 5.4 I explained in some detail why I chose to interview participants individually rather than observe them as they went about their work. However, recorded talk from professional meetings, case conferences and meetings with parents would have presented examples of how constructions are employed in action and how they might be refuted or accepted by others whose views are not represented here, including managers, parents and children.

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[1] D'Cruz (2000: 8.13) acknowledges these dilemmas:

> *Whilst occupying an identity as pseudo-supervisor I was trying to hold together both the 'realist' and 'relativist' ethical and epistemological positions, rather than polarise them. By this I mean I acknowledged as 'real', children's reported experiences of oppressive practices, and the social, legal and ethical necessity for child protection intervention, and all the contradictions of power it presents to practitioners, knowing this from my own experiences as a social worker. However, I also wanted to explore the 'relative' meanings given to these reports called 'child maltreatment' and how and when practitioners categorised them as such.*

Thus the design of the study has limited how far I can claim that the stories the professionals present are representative reflections of the full range of their interactions with parents. There are also questions about how representative my participants were of the full range of practitioners who work with parents with learning disabilities. The number of participants and interviews was relatively small, necessitated by the time-consuming and labour-intensive nature of discourse analysis. Participants were drawn from only one inner city catchment area, and the rather arbitrary spread of professionals among my sample also mean that I must be tentative about how far my findings can be generalised.

Nevertheless, I do feel that I can make claims for the applicability of my research findings beyond my small group of participants. Because of my assumption that the constructs or discourses I have identified are socially constituted, and linked to social and institutional structures, I presuppose that they form part of the 'discursive economy' which is widely available to other social actors.

In Chapter One I explained why I did not interview parents. My focus was on professionals' constructions, and how these shape what can be said about parents and possibilities for professional practice. This area has not been systematically researched in the past. My chosen method of discourse analysis, which requires a detailed, in depth examination of recorded talk inevitably restricted the number and range of interviewees. Nevertheless, I do feel that the absence of accounts provided by parents themselves may skew the overall findings of the research. Narratives provided by people with learning disabilities can reveal 'hidden' or unexpected experiences, including stories of competence, self-determination and resistance (Goodley, 2000). Previous research has elicited views of parents with learning disabilities about professional support in general terms (Booth and Booth, 1994; Llewellyn 1995; Llewellyn et al., 1998). In relation to my own research questions I feel that parents' own self-presentations and their conceptualisations of

professionals would have been an extremely useful adjunct and complement to the professionals' accounts.

The absence of the voices of parents with learning disabilities may have contributed to what appears as dearth of positive stories in this study. This reinforces the idea that these parents constitute a social problem, whether because of their intrinsic deficits or because of societal responses. The likelihood is that the practitioners who responded to my original request for participants were those who wished to explore and reconsider difficult experiences, rather than those who wished to recount positive stories. It is perhaps also more likely that parents who are managing at least adequately would not be 'known to' specialist learning disability or child protection services.

Many parents with learning disabilities have limited contact with any kinds of services, especially those from some ethnic minorities, where because of support from extended family members children are rarely placed on at risk register (O'Hara and Martin, 2002). I did not explicitly address issues relating to culture and ethnicity in this study, but these factors undoubtedly have a profound impact on the experiences of parents and their relationships with professionals. My own experiences with the Bangladeshi community in my workplace in Tower Hamlets in East London have convinced me that Bangladeshi parents with learning disabilities have different life experiences to the parents talked about in this study, and professionals have different understandings of them related to culturally specific practices and social structures (Hepper, 1999).

12.4 Contributions of the research: implications for professional practice

Social constructionist research starts with the assumption that existing and taken-for-granted ways of thinking and acting are contingent on particularly historically and culturally determined circumstances, rather

than universally true for all time. In this study I have described how different conceptualisations of parents with learning disabilities have been dominant at different times, and how these have shaped and moulded by prevalent historical preoccupations. This analysis creates space for challenging the universal relevance of contemporary constructions. In this way, as Hacking (1998) has pointed out, social constructionist research can be used to advance socio-political aims by contextualising and localising dominant understandings, creating space for imagining alternatives. Rossiter (2005) had advocated that practitioners use findings from discourse analysis to develop 'historical consciousness' to avoid reproduction of historical traumas, by noting the impact of historically located discourse on present talk. In the case of parents with learning disabilities these traumas have included not only the overtly oppressive consequences of eugenic ideology, such as sterilisation and institutionalisation, but also the 'missed opportunities' I have identified related to more recent Normalisation and Social Model ideologies.

Discourse analysis can also help practitioners develop an awareness of which discourses are dominant, which are marginalised or even suppressed altogether. This study suggests there are constructions which often get left out of discourses in use: constructions of parents with learning disabilities as resourceful and skilful; constructions of children as capable and autonomous; constructions of parenting as 'distributed competence' (Booth and Booth, 1994) where the ability of elements within the wider family or social system to contribute to the successful raising of children is acknowledged; constructions of responsibility to care for children which extends outside the realm of the individualised nuclear family to neighbourhoods, schools, the media, and public agencies; constructions of professionals as allies and advocates, acting in solidarity with disabled people. It is these alternative accounts which can inform more responsive practice.

This study has allowed us to examine how professionals construct parents with learning disabilities through use of language strategies which promote

particular versions of reality, dividing the 'normal' from the 'abnormal'. These practices of regulation have been shown to limit what is expected both of parents and of practitioners. Moreover, the research has clarified these professionals' relationship to power (or 'power/knowledge'), describing how they both transmit power through disciplinary practices, and are themselves acted on by power often in subtle and indirect ways, through the process of subjectification whereby they create themselves as particular kinds of individuals.

> *Conformity is not the result of overt force that visibly bends the will of those subject to its operation; conformity results from the constant working of invisible constraints that bring us all toward the same 'normal' range of practices and beliefs* (Covaleskie, 1993)

Rossiter (2005) has also argued that an examination of the subject positions available within different discourses provides opportunities for practitioners to take a more distanced, reflexive stance vis a vis their practice and examine their own investments in particular positions, and the rights and obligations they entail. The requirement for practitioners to be reflexive is part of contemporary service rhetoric in health, social care and education sectors (the journal 'Reflective Practice' is dedicated to this endeavour). However, there are dangers that 'reflexivity' can be reduced to an exercise in name-checking practitioners' social location, their gender, class or ethnic position in such as way that inequalities between professionals and clients become reified and unchallenged (Heron 2005).

An awareness of how practitioners are positioned and position themselves within discourses relating to parents with learning disabilities can afford greater choice to reject or accept these positions. More conservatively, it may support a recognition that available positions may present sometimes intractable dilemmas and contradictions, that certain choices in the conduct of practice may not be available. Confronting this possibility permits practitioners to avoid internalising and individualising the contradictions that are played out in practice by identifying the links between dilemmas in practice and widespread structural inequalities. This

study encourages professionals to combine elements of an analysis of wider social and economic structures with an awareness of how they may actively mobilise particular discourses and positionings to advance the interests of parents with learning disabilities and their children.

This study also raises further questions which practitioners need to address: how to engage in a discourse about people with learning disabilities that acknowledges their disability without either trivialising or over-emphasising it; that acknowledges the power that we can access as a professional, without being oppressive; that supports people with learning disabilities to have control over their own lives, without subjecting them, and other vulnerable people to danger and exploitation.

12.5 Reflexivity : on completing this PhD

I started out hoping that this research would give me some answers to questions which were important to me in my professional life working with parents with learning disabilities. I particularly wanted to improve my practice so that I would work more effectively with these parents. Now I have come to the end of this project, I can acknowledge that the issues that I have been examining, about the nature of competence, about parenting and childhood have resonated with concerns in my personal and family life as well.

I have become more aware of how much is stacked against parents with learning disabilities. I have already mentioned how this PhD has been an extended, part-time project that I had to fit in around professional and family responsibilities over a nearly ten year period. This time period has seen many important social developments; a change in government, the launch of Valuing People in 2001 and the new Children Act in 2004, an acceleration of the processes of globalisation and the 'digital age'. I wondered whether my original research questions would lose their relevance, that social trends would change direction. However, I do not

believe that this has happened. I have noted an increasing emphasis on the regulation and control of parents and an equation of disability and difference with risk to children. There is still little space to acknowledge the strengths and competencies of parents with learning disabilities in dominant discourses relating to disability, parents and children. Discourses of risk and children's vulnerability can overwhelm knowledge about parents' concern and commitment to their children, as well as their progress in learning new childcare skills.

Nevertheless, the process of doing the research has brought about developments in my own professional life. I have become more skilled in identifying and engaging with these dominant discourses on their own terms when they emerge in discussions and meetings about parents with learning disabilities. I have become more aware of the conflicts and ambiguities these discourses and positionings present for professionals and how they relate to culturally and historically specific preoccupations in the wider context. Appreciating the dilemmas and difficulties faced by fellow practitioners has helped me take a less blaming and confrontational stance, which I hope has made me more effective as an advocate and ally of parents with learning disabilities.

Looking at how risk is socially constructed has given me the confidence to let my own children take on new experiences and responsibilities. Identifying pressures to assume as a parent an individualised responsibility for my children's welfare has encouraged me to develop my networks and request that others (friends, family, teachers) involve themselves in taking an active interest in my children's wellbeing. Though I have not emphasised this aspect in writing up this PhD, my research does have implications for how we understand children and how dominant constructions of parenting and childhood underestimate their competences, resilience and capabilities. Inevitably this understanding has increased by appreciation and respect for my own children, without whose tolerance and support this work could not have been completed.

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PARENTS WITH LEARNING DISABILITIES

FEASIBILITY SURVEY

To: *Community Midwives*
Health Visitors
Ante-natal nurses
Social Workers
Clinical and Counselling Psychologists
Non-Governmental Organisations for People with Learning Disablities

This survey is part of a larger study looking at the experiences and needs of parents who have learning disabilities ("learning disabilities" is another term for "mental handicap"). The eventual aim of this study is to look at ways of making services for parents who have learning disabilities more responsive to their needs.

I would be very grateful if you could answer the questions below overleaf. The questionnaire takes less than 10 minutes to complete. For the purposes of this questionnaire, someone with learning disabilities is someone who has been to a **special school** because of some marked intellectual disability, or someone who has had contact with **specialist services** for people with learning disabilities. If you do not know much about your client's background, other indications that they have a learning disability might be:

* Inability to travel alone on public transport
* Reading and writing problems. Either unable to write, or writes only minimal factual information, or reads with limited comprehension.
* Problems managing money and budgeting
* Difficulties in keeping up with routine demands (e.g. keeping appointments, organising domestic tasks, prioritising activities)
* Requiring help from a "supporter" not usually expected for an adult (e.g. help filling in forms, transportation, making appointments)

If your client has four or more of these characteristics, it is probable that they would be identified as having a learning disability

Deborah Chinn
Clinical Psychologist
XXX Multi-Disciplinary Team for
People with Learning disabilities

QUESTIONNAIRE

NAME.....

OCCUPATION.....

CONTACT ADDRESS.....

TELEPHONE NUMBER.....

INSTRUCTIONS: Please tick one response for each question.

1. Have you ever worked with a parent who has learning disabilities?

   a) YES
   b) NO

2. Have you worked with a parent who has learning disabilities within the last 12 months?

   a) YES
   b) NO

3. Are you working with a parent who has learning disabilities at the moment?

   a) YES
   b) NO

4. Would you be willing to invite parents with learning disabilities that you are working with to be included in a study on the experiences and needs of parents with learning disabilities?

   a) YES
   b) NO

5. Would you yourself be prepared to be interviewed for a study on the experiences and needs of parents with learning disabilities?

   a) YES
   b) NO

THANK YOU VERY MUCH FOR FILLING IN THIS QUESTIONNAIRE

PLEASE RETURN IT TO ME IN THE S.A.E. PROVIDED

Professionals talk about Parents with Learning Difficulties

Deborah Chinn

Tel: XXXXX (home)
XXXXX (work)

email: XXXXXXX

Thank you very much for showing an interest in my research project. I would like to take this opportunity to tell you about my research project, about myself, and what you can expect if you agree to take part in this project.

The research project

The aim of the project is to talk with people who work with parents with learning difficulties from a range of different professional backgrounds, and find out about their experiences in working with these parents. People working with these parents sometimes find their work is quite complicated, often with lots of different agencies involved, and I am interested in finding out how workers make sense of their work and what barriers they may encounter. I hope that the findings from the project will help us do a better job of working with families with parents with learning disabilities. It might throw up some ideas about the sort of training or organisational change that would help.

The research project has received ethical committee approval from the XXXXX Local Research Ethical Committee. Most of the people I have talked to so far have worked in XXXXX, though I am keen to talk to people with special skills who work elsewhere.

Personal profile

I am a clinical psychologist, working in a multi-disciplinary team for people with learning difficulties in London. I do work with parents with learning difficulties as part of my contribution to the team. However, this research project is not part of my NHS work. I am doing the research as a part-time PhD student at the Institute of Education which is part of London University. My supervisors are Professor Priscilla Alderson and Dr Phillida Salmon.

The Interview

If you agree to take part in this research project I will arrange to meet with you at a time and in a place which is most convenient to you. I am happy to meet you at your place of work. The interview lasts an hour or so. The questions are open-ended, about your experiences with parents with learning difficulties. I have a few questions that I ask everyone, but mainly I am interested in listening to points you would like to bring up, relating to this work.

I tape record the interviews and afterwards transcribe them. After I have finished transcribing the interviews, I will erase them from the tapes. I will send you a copy of the transcription of your interview, in case I have written something down wrong.

Confidentiality

When I do the transcriptions I remove the real names of the person I am interviewing, the organisation they work for and the clients that they are talking about. None of these details are stored on my computer and they will not appear in the write-up of the research. When I write up the research I will quote from the transcriptions with all identifying information removed. This means if you tell me any information about yourself or a client that means that someone else might be able to identify you or the client, this information will be removed.

Feedback

I aim to finish the research project in 2005. When I am finished I will send you a summary of my findings and any recommendations that come from the findings. I will be happy to meet with you or your organisation again at that point to talk more about the findings of the project.

Please feel free to contact me at any time if you have any queries about this project.

Thank you

Deborah Chinn